

December 21, 2007

Dear Jeanne *Baldwin*

It was good to get your Christmas letter yesterday and catch up with the news of the family. They seem to be doing very well indeed, as do you. May 2008 be a rewarding one for you all.

We wanted to hasten and explain John's comment about Ivan, and since he's busy working on his World War II novel even as I write this, I thought I'd volunteer as family scribe.

Ivan is feeling very well indeed, and is working with unflagging energy to finish the current manuscript. He does have a new immune system, which his body seems to like a lot. Let me explain the circumstances.

About seven years ago our beloved family doctor, Pat Kato, noticed a slight deviation in a routine blood test: his level of monoclonal protein was a bit high. From then on he was under surveillance and about a year and a half ago the protein level began rising toward unacceptable heights. If unchecked, great concentrations of protein can damage kidneys, among other things. And at some point the condition could be expected to mutate into multiple myeloma.

Because he's in such good health he was offered what's called the gold standard of treatment, a stem cell infusion, where his own blood cells were extracted, cleaned and frozen, and then returned to him after his "old" immune system had been eliminated. His hematologist pronounced his recuperation remarkable.

With preliminaries, including a couple of months of nasty medicine, the whole procedure took several months at the start of the year, but Ivan continued to work at his writing and he was never hospitalized. We had made plans to see John and Darl, but the timing coincided with the stem cell infusion itself, and so we couldn't make that work. We hope they'll have another chance to visit.

Ivan goes about his normal life and is checked -- sophisticated blood test -- every four months. He calls himself a poster boy for prevention, thanks to the excellent doctoring we get from our Group Health co-op. While there are no guarantees that he won't have to have more doctoring eventually, his hematologist's chief assistant did admit that with Ivan they were trying for a "virtual cure."

So that's the story. Ivan chose not to burden dear friends while he was going through the process except as they needed to know, and when we had to cancel out on the Prestbos we told them.

All is well here as Christmas and a new year come round once again. Would you

believe that Ivan is still producing lettuce from his garden, along with more seasonal items such as spinach and kale? We plan fruit salads for dinner tonight, with much of the fruit from our freezer. And we have regular homegrown side salads most nights of the week. As you might imagine, Ivan takes super good care of the lettuces: some are in coldframes, which are kind of small greenhouses, about two by three feet, with tops that open as weather allows. His other beds he covers with frost blankets as needed. For extra cold nights, which around here means into the 30s, he has rigged lights for warmth.

On the social front, we've recently enjoyed dinner downtown, at a very nice restaurant, with Ann and Marshall, who are just fine. Daughter Sarah is expecting her second son in March and seems unfazed by pregnancies. (She's small, but she's in terrific shape.) As for Ann and Marsh, they travel quite a bit and very much enjoy their second home on the Oregon coast whenever they can get there. We have a standing invitation and hope to get down in the spring, maybe even to celebrate our 43rd anniversary!

Finally, a book note. After Ivan wrote our Christmas letter, he found out that *The Whistling Season* has been nominated for the International IMPAC Dublin Literary Award, which is the richest in the world at 100,000 Euros. The catch? More than a hundred other novels (all must be in English or translated) also are nominated by libraries around the world. What particularly delights us is that, of 22 American public libraries which made nominations, three -- Lincoln, Denver and San Diego -- chose *The Whistling Season*. So it's a great compliment. We aren't holding our breath for the book to be short-listed in April, however, since we figure that the international panel of judges -- no Americans -- won't "get it" about a one-room schoolhouse in Montana.

That's all for now. Merry Christmas, Jeanne.

Love,
Carol

I hate, formalise aspect
of this, but I know
you'll understand why
I had to resort to it

I don't want to make it any more dire than it is, but I have a feeling the doctors have been following me for about a year ago the protein was not attended to, it could turn into something absolutely early--it's called amyloidosis. If they're healthy they're able to hit it before it's too late. I hear it in the dry voice--I still don't want to say anything until now, nobody needed that kind of news dropped on them over the holidays. So you're the first to know. I know you'll need to talk to Becky, but I'd just as soon tell her first.

The writing, by the way, goes okay in spite of what I'm putting into myself. One of the drugs peeps up the mind the four days a week I'm on it, while it plays games with the rest of me. Colossal constipation, for instance. So writing is therapy for this drug therapy, as they call it. I've got over 50,000 words on the next book, pretty close to half done. There is going to be an interruption down the line, sometime this spring. The optimal treatment for this, which they're able to give me because of the good health, is a stem cell transplant. That's pretty rigorous and will probably knock me on my butt for six weeks or more. Then the doctors say a month or so after that I should feel normal and my blood has a fresh start without the evil protein. I feel I'm getting top of the line medical care, and the Hutchinson Cancer Center out here is a world leader in stem cell stuff, so I think I'm in good hands.

Anyway, this is what it is, I just have to tough through it for a while. I feel pretty good, although the one drug that wires me up leaves me a bit spacy a few days later. Anyway, Carol and I are going about life as usual as much as we can. I hate to drop this on you, but better you know.

Life goes on
until proven
otherwise

~~Keep it to~~
Keep yourself -
telling selected
trusted friends -
David & Mari
tomorrow

I don't want to make a big a big deal of this, and it's going to sound more dire than it is, but I have a blood condition that I'm under stiff medication for. The doctors have been following this in me for six years, and it stayed benign, but about a year ago the protein level in my blood tests started to spike. If this weren't attended to, it could turn into myeloma, blood cell cancer. So they've caught it absolutely early--it's called "indolent" in doctorspeak--and because I'm perfectly healthy they're able to hit it hard. But it's pretty strenuous drugs--you can maybe hear it in the dry voice--I started on them the first of the year. Didn't see any use in saying anything until now, nobody needed that kind of news dropped on them over the holidays. So you're the first to know. I know you'll need to talk to Becky, but I'd just as soon tell her first.

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I don't want to make a big deal of this, and it's going to sound more dire than it is, but I have a blood condition that I'm under heavy medication for. The doctors have been following this in me for six years, and about a year ago the excess protein in my blood tests started to spike. If this weren't attended to, it could turn into myeloma, blood cell cancer. So they've caught it early, and because I'm perfectly healthy otherwise they're able to hit it hard. But it's strenuous drugs--you can maybe hear it in the dry voice--I started them the first of the year. Nobody needed that news dropped on them over the holidays, so here it is now. I'd appreciate your holding it to yourself and Lee--I haven't broken this to my editor and agent yet, until I could see how it's going. And we've got various friends to let know what's going on with me.

So, that's the thing. It is what it is, I just have to tough through it. I feel pretty good, although one of the drugs kind of wires me up and leaves me a bit spacy a few days later. Anyway, we're going about life here as usual as much as we can, and we'd love to see dear friends.

excuse - former^{fore}
aspect of this,
but you'll
understand

Dear

This is, I suppose, the opposite of the many weeks ago. But it's the clearest way I medical turn of events that will affect me for year, I began drug therapy for an early stage cancer of the blood cells. The alarming sound dexamethasone, and a minimum dose of Cou case such as mine.

And--here's a paradox--precisely because I am otherwise in perfectly good health, at the culmination of these month-long phases of drugs will come what is called the "optimal" treatment for myeloma, a stem-cell transplant. Doctors of course are doctors, professionally positive, but mine at Group Health hematology and his cohort at the Hutchinson cancer center have told me over and over that because my case has been caught so early, I am at "the best end of the spectrum" and should be around a lot longer than otherwise with my own stem cells replacing the myeloma-prone ones. Carol and I take that as the good news amid all this.

Any of you who have seen me lately, feeling fine and vigorously riding the wave of *The Whistling Season's* success, may be justifiably surprised not to have had any sign of this. I chose not to say anything until now because I simply saw no good to be achieved in dropping this on people during the holidays, or for that matter, until my treatment became an obvious part of life. Hence, this message this way. E-mail seemed to me a particularly denatured way of telling you, and the reverse would be true in trying to let so many sets of friends know by phone or face to face--that loomed to me as simply too emotionally grueling at a time when I need all the energy and steadiness I can muster. Besides, I believe you're all used to me habitually thinking onto paper. In that spirit, here are a few diagnosis/prognosis points you might be wondering about:

--This has been six years coming. Early in 2001, a routine Group Health physical spotted a somewhat higher than usual proportion of M proteins in my plasma cells. That benign condition required watching but stayed stable until last February when the level of those proteins, which can abnormally build into myeloma cells, began to spike. So, before those myeloma cells do form and begin to affect my bone marrow, treatment is needed.

--The stem-cell transplant process will be undeniably rigorous. However, my doctors exude confidence that they will get me into remission with it; the scenario sketched for me is a tough two weeks after transplant as the new cells take hold, then I should feel “better” within a month, and “normal” a month or two after that.

--My mood is not bad, to use the Scotch term for pretty good. I don't have any "Why me?" about this. I have always figured that life in its luck of the draw is constantly asking any of us, "Why the hell *not* you?" This treatment/transplant regimen mainly will take perseverance, which I generally have quite a lot of, and any I don't have, Carol does.

She and I intend to go about life as normally as my temporary diet of medicines will let us. So, don't hesitate to offer social occasions as usual, and we'll do the best we can, too. Meanwhile, know that I am bolstered by my affection for each and every one of you.

implacably?

17277 15th Avenue N.W., Seattle, Washington 98177
(206) 542-6658

phone conversation

(Possible comments after you've laid out the situation.)

Please limit your discussion of this, and keep it off the Web, so that an ill-informed rumor mill doesn't get started. (You remember what happened when a tale without foundation came out of Billings.)

I'd like to keep low profile in publishing, where I've informed only my agent, my editor, and my publicity manager. In Montana, we're telling just one friend and ~~searing~~^{tearing} her to secrecy.

I'm in good spirits and intend to go on with life as usual, working and enjoying your company. If, from time to time, I have to say "Let's reschedule," you'll know I'm into one of the more difficult parts of the treatment.

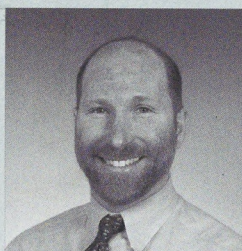
J & J

Sorry abt the way of doing this

people
~~*know*~~

I hate the formlike aspect of this, but with so many friends ~~that~~ I have to let know
what's up, I ^{*I'm sure*} ~~know~~ you'll understand.

Xmas at your place was splendid. See you again when we can.



Steven Ginsberg, MD

Adult Hematology/Oncology

Office Location Capitol Hill Campus

Joined Group Health 1998

Education BS/MS, chemistry, Emory University, Atlanta, Ga., 1980; MD, State University of New York Downstate Medical Center College of Medicine, Brooklyn, N.Y., 1984

Advanced Training Residency in internal medicine, State University of New York Kings County Hospital/Downstate Medical Center, Brooklyn, N.Y., 1984-87, chief medical resident 1987-88; fellowship in hematology and medical oncology, Yale-New Haven Hospital, New Haven, Conn., 1988-93; fellowship, Bone Marrow Transplantation Program, Vancouver General Hospital, Vancouver, British Columbia, 1995-98

Certification Board-certified in internal medicine, hematology, medical oncology

Philosophy of Care "I believe in a patient-oriented approach to medical care. Decisions should be based on honest dialogue between physician and patient."

Special Medical Interests Stem cell rescue and transplantation, leukemia, and lymphoma

Personal Interests Running, hiking, golfing, and food

Exhausted by the amount of time spent on the toilet. Not to get into details, but greatly more seemed to come out of me than I had taken in. The elimination system of the body...in high gear.

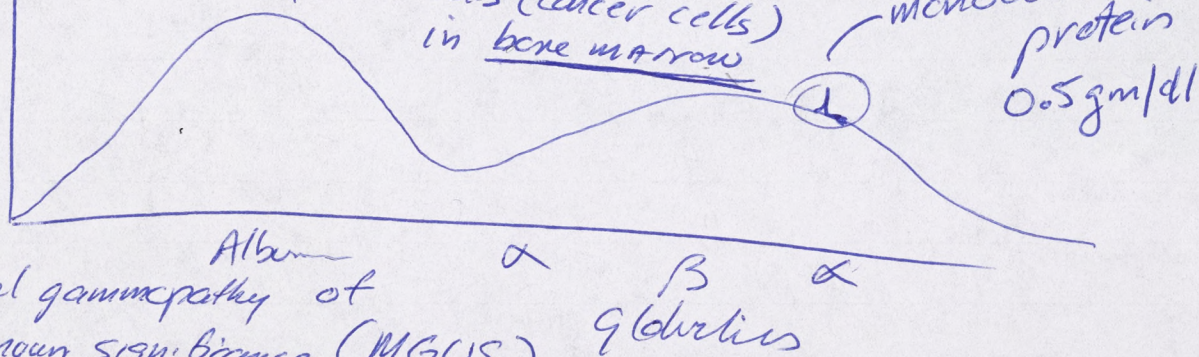
(in early treatment)...incalculably lucky. (new graf) yet I have a cancer that is (all but) sure to get me in the end. (when all is said and done)

As far as we know, it's way better than death.

Multiple Myeloma

- monoclonal protein - small in your case
- anemia - minimal

- $\uparrow$ calcium
- $\uparrow$ creatinine (measures kidney function)
- bone "lesions" (x-ray)
- protein in urine
- plasma cells (cancer cells) in bone marrow



Monoclonal gammopathy of
unknown significance (MGUS)

GROUP HEALTH COOPERATIVE***Department of Radiology***

PLACE ARPA LABEL HERE

☐ Return Film to Provider☐ Stat Reading☐ Pregnant☐ Diabetic☐ L & I

Patient Name:

Consumer Number:

Date of Birth:

Primary:

Phone #:

Requesting:

ARPA Acct #:

Plan:

Ht _____ Wt _____

Patient phone: (home) _____

(work) _____

Examination:	ICD9 Code:
Diagnosis:	History:
Precautions / Allergies:	
Additional report to:	Provider #:
Appt Date:	Appt time:

Dr. Ginsberg, 2 Dec. '08:

Told him how I feel on the Prednisone regimen at the 10 mg. level:

--Although I'm not as fumbling as I was on the higher dosages, there's still some indecision, a sense of not quite being myself mentally. And still some forgetfulness if I try to line up two or three tasks in a row.

Possibly I can be taken off Prednisone some time from now, he said, if increasing the Thalidomide dosage succeeds in lowering the two protein rates. So, he raised the Thal dosage from 50 mg. to 100 mg., with 150 mg. possibly ahead. (*at then 200, usually "the minimum"*)

--Both protein rates were up slightly from the previous test; the diciest one, urine protein, was 354 mg. compared with 336 in Oct., and the total protein is over 2000 mg, up from 1972 mg.

This was the last session with him, after eight years of treatment, and it was wrenching for both of us. Before I could him ask him the parting question--if you had been diagnosed with my condition, what doctor would you choose?--he decided to pass me along to Dr. Chen, scheduling me into a 40-minute session on Feb. 5 so Chen and I can familiarize ourselves. This was another example of Steve Ginsberg zeroing in on something beyond our ken; the hematology/oncology letter announcing Steve's departure makes it sound as if Chen is available only in Everett and Bellevue, although he's actually at Capitol Hill on Tuesdays and Thursdays.

Steve, citing "terrific stress" this year without giving us any details, is moving on to Highline Hospital in W. Seattle. He told me he's available to me there, if it ever comes to that.

Dr. Ginsberg, 9 Sept. '08:

How I feel on the Prednisone/Thalidomide regimen at the 50 mg. level:

--Some hesitation on focusing in when a new topic is brought up. Along with it, forgetfulness if I try to line up two or three tasks in a row.

--Nervousness, maybe 2 or 3 on a scale of 10.

--Voice tremor that I have to consciously overcome.

--Not entirely certain of the perimeter of my body; I have to take extra care not to bump into things or knock things over.

--A slight shakiness, particularly on the day after I take Prednisone; a bit of tremble in the fingers, and a feeling of tremulousness in the body and legs when I lie down at night, which ceases after a few minutes.

--Numbness in the feet, particularly the left one; some hand cramps and a general tightness in the hands.

--Considerable flatulence; bowel movements okay, recently.

With my new book being published, between Sept. 16 and Nov. 13 I have a couple of speeches to give, several public readings and an hour-long National Public Radio interview. If the dosage were to be increased--particularly the Prednisone?--I'd be concerned about my ability to function at these events.

followup:

After reading the above, Dr. G. cut the Prednisone dosage to 25 mg. every other day; I am to e-mail him Monday, Sept. 15, to let him know if this alleviates the symptoms.

--The 50 mg. Thalidomide is already a minimum dose, he says; average is 200 mg. He remarked that this dosage probably will have to go up "sometime."

Contrary to our expectations, he was not alarmed at the increase ("a little worse," he called it; from 14% to 15%) in the urine protein; he said we have only this one reading on it so far, during this drug regimen. The monoclonal protein reading was down from .3 to .2, essentially unchanged, and he said the rest of the blood test results were okay or better.

He wanted to see me again in six weeks. The schedule:

--Oct. 7, 8 a.m., Pamidronate infusion

--Oct. 12, 24-hour urine test

--Oct. 13, 8 a.m., N'gate blood test and take urine test in

--Oct. 23, 9 a.m., Dr. G.

--Nov. 4, 8 a.m., Pamidronate infusion

After-Visit Summary

This document contains confidential information about your health and care. It is provided directly to you for your personal, private use only.

Visit Information

Appointment
Information

<u>Date</u>	<u>Time</u>	<u>Department</u>	<u>Provider</u>
12/02/2008	9:40 AM	CSC ONCOLOGY	Steven Ginsberg, MD

If you have questions or need further information, call this department at 206-326-3000 or send a secure message to your provider.

Vitals

<u>Blood Pressure</u>
142/70

Weight

156 lb 9.6 oz (71.03 kg)

Reason for Visit Follow-up Care

Diagnoses MYELOMA [203.00S]

Patient Information and Follow-up

Patient

Instructions blood and urine testing 1 week prior to next visit
increase thalidomide to 100 mg daily
continue prednisone at current dose

THUR Feb 5 @ 9:00 AM Chen

Follow-up Disposition

Return in about 2 months (around 2/2/2009) for 40 min appt with Dr. Chen.

Lab Tests Due

This section lists all lab tests you need to do. This may include tests ordered at previous visits. If a listed lab test wasn't done during today's visit, go to any Group Health medical center for that test. Your test should be done on the due date or as soon as possible after that date.

<u>To Do</u>	<u>Order</u>	<u>Due Date</u>	<u>Provider</u>
	CREATININE [82565.002]	11/29/2008	GINSBERG, STEVEN S
	CBC/PLT/DIFF (GHC) [85025.003]	11/29/2008	GINSBERG, STEVEN S
	BUN [84520.001]	11/29/2008	GINSBERG, STEVEN S

Lab Tests Due continued

<u>Order</u>	<u>Due Date</u>	<u>Provider</u>
ELECTROPHORESIS SERUM PROTEIN (GHC) [84165.003]	11/29/2008	GINSBERG, STEVEN S
CREATININE [82565.002]	11/29/2008	GINSBERG, STEVEN S
CALCIUM [82310.001]	11/29/2008	GINSBERG, STEVEN S
ELECTROPHORESIS-URINE PROTEIN (GHC) [84165.004]	11/29/2008	GINSBERG, STEVEN S

Upcoming Lab Tests

This section lists all lab tests you need to do after today. This may include tests ordered at previous visits. Go to any Group Health medical center for these lab tests. For orders with an "available" date, go on that date or as soon as possible after that date.

<u>Recurring Orders</u>	<u>Order</u>	<u>Provider</u>	<u>Ordered</u>	<u>Interval</u>	<u>Ends</u>
	CBC/PLT/DIFF (GHC) [85025.003]	GINSBERG, STEVEN S	6/2/2008	Every 12 Weeks	6/2/2009
	BUN [84520.001]	GINSBERG, STEVEN S	6/2/2008	Every 12 Weeks	6/2/2009
	ELECTROPHORESIS SERUM PROTEIN (GHC) [84165.003]	GINSBERG, STEVEN S	6/2/2008	Every 12 Weeks	6/2/2009
	CREATININE [82565.002]	GINSBERG, STEVEN S	6/2/2008	Every 12 Weeks	6/2/2009
	CALCIUM [82310.001]	GINSBERG, STEVEN S	6/2/2008	Every 12 Weeks	6/2/2009
	ELECTROPHORESIS-U- RINE PROTEIN (GHC) [84165.004]	GINSBERG, STEVEN S	6/2/2008	Every 12 Weeks	6/2/2009
	CREATININE [82565.002]	GINSBERG, STEVEN S	8/11/2008	Every 4 Weeks	8/11/2009
	CBC/PLT/DIFF (GHC) [85025.003]	GINSBERG, STEVEN S	10/23/2008	Every 6 weeks	10/23/2009
	BUN [84520.001]	GINSBERG, STEVEN S	10/23/2008	Every 6 weeks	10/23/2009
	ELECTROPHORESIS SERUM PROTEIN (GHC) [84165.003]	GINSBERG, STEVEN S	10/23/2008	Every 6 weeks	10/23/2009
	CREATININE [82565.002]	GINSBERG, STEVEN S	10/23/2008	Every 6 weeks	10/23/2009
	CALCIUM [82310.001]	GINSBERG, STEVEN S	10/23/2008	Every 6 weeks	10/23/2009
	ELECTROPHORESIS-U- RINE PROTEIN (GHC) [84165.004]	GINSBERG, STEVEN S	10/23/2008	Every 6 weeks	10/23/2009

Updated Medication List

This section lists the medications you have reported you are currently taking, in addition to new medications and supplies ordered and changes made at this visit. If you have any questions about your medications, please contact your pharmacist.

THALIDOMIDE (THALOMID) 50 MG ORAL CAP

Instructions: TAKE ONE CAPSULE DAILY. AUTHORIZATION:
1568399/CONFIRMATION:1466254

CALCIUM CARB-VIT D 600 MG-200 UNIT ORAL TAB

Instructions: TAKE 1 TABLET TWICE A DAY

Updated Medication List continued

PREDNISONE 20 MG ORAL TAB

Instructions: TAKE 1 TABLET (20MG) EVERY OTHER DAY.

PREDNISONE 10 MG ORAL TAB

Instructions: TAKE ONE TABLET EVERY OTHER DAY

RANITIDINE 150 MG ORAL TAB

Instructions: TAKE ONE TABLET TWICE DAILY

Health Profile

Remember to fill out a Health Profile every year. You'll get a personal report with suggestions on how to improve your health and lower your risk of certain diseases. For access to the Health Profile, log in to MyGroupHealth for Members at www.ghc.org. (You'll need to upgrade your online account to get enhanced services. Then you can also view your online medical record, exchange secure messages with your providers, request appointments, and refill prescriptions online.)



GroupHealth

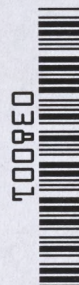
November 24, 2008

IVAN DOIG
17277 15TH AVE NW
SEATTLE WA 98177

Group Health Cooperative
Customer Service Center

P.O. BOX 34590
Seattle, WA 98124-1590

1-888-901-4636
www.ghc.org



Dear Ivan Doig,

We are sorry to inform you that Dr. Steven Ginsberg will be leaving his Group Health practice. His last day of patient care will be December 31, 2008. We will continue to make every effort to provide you with state of the art hematology and oncology care in a supportive setting.

Dr. Kurt Norman will be taking over for Dr. Ginsberg in Seattle. Dr. Norman has completed a fellowship in oncology at Stanford University, and has two and half years of practice experience.

For those of you in Everett, Dr. Eric Chen will be the oncology provider. If you live on the Eastside, we provide cancer care at the new Bellevue Specialty Center. Drs. Eric Chen and Eric Feldman are the providers at that location.

Group Health understands that your relationship with your provider is very important to you. We want to help make this change as easy as possible for you.

We continue to offer a variety of highly qualified providers to give you the care you need. Please take the time to think about your options and consider which location you would like to receive future care at. Our phone numbers are: Seattle 206-326-3111, Bellevue 425-502-3690, and in Everett 206-326-3109. Please feel free to call and have our staff answer your questions. If you already have an appointment after December 31st, we will schedule you with a new provider. If you would like a specific provider or change the location of your appointment please call our office.

Please accept our apologies for any inconvenience that may be caused by this change in providers.

Sincerely,

Eric Feldman, MD
Service Line Chief of Hematology/Oncology
Group Health

Dr. Ginsberg phone call, 29 Sept. '08:

215 848

206 542-6658

This past week I've been having more hand cramps than before. I wonder if we can do anything to mitigate those. Also, I'm feeling some effects from Prednisone even at the 25 mg. level--some of the bodily uncertainty and mental hesitation I told you about. Would it be possible to go off Prednisone or try a smaller dosage until I see you next, on Oct. 23? I'm available by phone today after 1 o'clock. Thanks.

20 mg. Pred~~isone~~

Your Messages

Use this form to send a message about **non-urgent** health concerns to your health care team or the Consulting Nurse Service. You'll get a confidential reply in your MyGroupHealth message inbox, usually by the end of the next business day.

Want an e-mail notice when a message arrives in your MyGroupHealth inbox? If so, we need your e-mail address: Please [update your profile](#) before typing your message.

Time limit: If you start to write a message but don't send it within 30 minutes, you will be automatically logged out. The message will be lost and you will need to start over. This is a security measure.

This communication will become part of the medical record for IVAN C DOIG.
Use this form ONLY for messages about the health of this person.

From: Ivan C Doig

To the office of: Ginsberg, Steven S

Sept. 15, 08

Subject: result of cutting Prednisone dosage

Message:

Maximum 5000 characters.

Your message will be answered as soon as possible, usually by the end of the next business day. If you have an urgent health concern or require a more immediate response, call your physician's office or the Consulting Nurse Service:

Western Washington: 206-901-2244, 253-596-3400, or toll-free 1-800-297-6877

Central Washington, Eastern Washington or North Idaho: 1-800-826-3620

Please observe the following guidelines when using electronic communication:

- Do not use electronic communication for urgent matters. Normal turnaround time is 24 hours.
- Remember that documentation of the electronic communication may become a part of your medical record.

The side effects are less; there's still a bit of shakiness, but handleable.

I'm ready to start the booktour. I don't feel we need a phone conversation.

Dr. Ginsberg, 9 Sept. '08:

How I feel on the Prednisone/Thalidomide regimen at the 50 mg. level:

--Some hesitation on focusing in when a new topic is brought up. Along with it, forgetfulness if I try to line up two or three tasks in a row.

--Nervousness, maybe 2 or 3 on a scale of 10.

--Voice tremor that I have to consciously overcome.

--Not entirely certain of the perimeter of my body; I have to take extra care not to bump into things or knock things over.

--A slight shakiness, particularly on the day after I take Prednisone; a bit of tremble in the fingers, and a feeling of tremulousness in the body and legs when I lie down at night, which ceases after a few minutes.

--Numbness in the feet, particularly the left one; some hand cramps and a general tightness in the hands.

--Considerable flatulence; bowel movements okay, recently.

With my new book being published, between Sept. 16 and Nov. 13 I have a couple of speeches to give, several public readings and an hour-long National Public Radio interview. If the dosage were to be increased--particularly the Prednisone?--I'd be concerned about my ability to function at these events.

prednis OK
25 mg Pred > 9/1!
10
12 - stop / OK thru week
25 mg
energy ⇌
OK w/ Thal
200 au.
up 5 time
6 wks / lab tests
start - Oct. 21
stay w/
cut to 25
e-mail # Mon.

After Visit Summary

This document contains confidential information about your health and care. It is provided directly to you for your personal, private use only.

Visit Information**Appointment**

Information	<u>Date</u>	<u>Time</u>	<u>Department</u>	<u>Provider</u>
	05/29/2008	9:00 AM	CSC ONCOLOGY	Steven Ginsberg, MD

If you have questions or need further information, call this department at 206-326-3000 or send a secure message to your provider.

Vitals Blood Pressure
100/64

Weight
153 lb 12.8 oz (69.76 kg)

Reason for Visit Follow-up Care

Diagnoses MYELOMA [203.00S]

Patient Information and Follow-up**Patient**

Instructions pamidronate infusion once a month
→ blood and urine testing 1 week before next visit with Steven Ginsberg, MD
calcium and vitamin D supplementation
begin thalidomide 50 mg every day
begin prednisone 50 mg every other day
Ramitidine

Follow-up Disposition
Return in about 4 months (around 9/15/2008) for follow-up/pamidronate.

Medications Ordered This Visit

Pick Up at
Pharmacy CALCIUM CARB-VIT D 600 MG-200 UNIT ORAL TAB
THALIDOMIDE (THALOMID) 50 MG ORAL CAP
PREDNISONE 50 MG ORAL TAB

Upcoming Lab Tests

This section lists all lab tests you need to do after today. This may include tests ordered at previous visits. Go to any Group Health medical center for these lab tests. For orders with an "available" date, go on that date or as soon as possible after that date.

Upcoming Lab Tests continued

Recurring Orders	Order	Provider	Ordered	Interval	Ends
	CBC/PLT/DIFF (GHC) [85025.003]	GINSBERG, STEVEN S	6/19/2007	Every 12 Weeks	6/19/2008
	BUN [84520.001]	GINSBERG, STEVEN S	6/19/2007	Every 12 Weeks	6/19/2008
	CREATININE [82565.002]	GINSBERG, STEVEN S	6/19/2007	Every 12 Weeks	6/19/2008
	CALCIUM [82310.001]	GINSBERG, STEVEN S	6/19/2007	Every 12 Weeks	6/19/2008
	ELECTROPHORESIS SERUM PROTEIN (GHC) [84165.003]	GINSBERG, STEVEN S	6/19/2007	Every 12 Weeks	6/19/2008
	ELECTROPHORESIS-U- RINE PROTEIN (GHC) [84165.004]	GINSBERG, STEVEN S	6/19/2007	Every 12 Weeks	6/19/2008

Updated Medication List

This section lists the medications you have reported you are currently taking, in addition to new medications and supplies ordered and changes made at this visit. If you have any questions about your medications, please contact your pharmacist.

TRAZODONE 50 MG ORAL TAB

Instructions: TAKE 1/2 TO 1 TABLET AT BEDTIME AS NEEDED FOR SLEEP

CALCIUM CARB-VIT D 600 MG-200 UNIT ORAL TAB

Instructions: 1 pill twice a day

THALIDOMIDE (THALOMID) 50 MG ORAL CAP

Instructions: 1 pill daily

PREDNISONE 50 MG ORAL TAB

Instructions: 1 pill every other day

Health Profile

Remember to fill out a Health Profile every year. You'll get a personal report with suggestions on how to improve your health and lower your risk of certain diseases. For access to the Health Profile, log in to MyGroupHealth for Members at www.ghc.org. (You'll need to upgrade your online account to get enhanced services. Then you can also view your online medical record, exchange secure messages with your providers, request appointments, and refill prescriptions online.)

Dr. Ginsberg's nurse's phone call, 30 May '08:

Ruth Ann responded to my e-mail message:

--Yes, I can have Temazapan and Lorazapam when I go on the Thal-Pred regimen in mid-June, but Dr. G. wants me to try to do without those for a few days at the start, to see how it goes.

--I do need to do a Thal protocol with her, after my Pamidronate infusion on June 16; she's to leave me a phone message next week with details about this.

--And I need to change the Pamidronate infusion dates to every 28 days, to coincide with the Thal issuance.

--No blood thinner this time.

As I understood it, Ruth Ann splits her time between Dr. G and the infusion center, and the Thal protocol details will depend on which spot she's working at then.

Thalidomide-Prednisone regimen

To: Steven Ginsberg, MD

From: Ivan C Doig

Sent: 5/30/08 9:06 AM

Dr. G., hi--Checked my diary on my '07 Thal-Dex regimen, and found some sleep lack and shakiness evidently due to the Thalidomide, that we had to medicate. I see you blessedly have me on 50 mg. this time, but to be prepared can I get Temazepam (Trazodone isn't as good) and Lorazepam when I pick up the Thalidomide etc. in mid-June? Do I need to go thru a Thal protocol with Lynn like last time, and if so, can we do it 6/16 after 7:30 Pamidronate infusion? And blood thinner this time or not? Lastly, I set up the Pam'ate dates a month apart as you said, but last time the Thalidomide was issued every 28 days--had I better change the Pam'ate dates to 28 days apart to coincide with picking up the Thal, or is the monthly schedule with a few days' lapse of Thal OK?
See you in Sept., we hope it's a good biking summer.--Ivan

Dr. G e-mail

May 29 '08

- Thal protocol w/ Lynn? June 16 or 13
- Pamidronate every 28 days instead of month, to match Thal?
- Tamazepam & Lorazepam
- blood thinner? ^{bleet anemia}
- Thal 1st xine: constipation; skin; neuropathy
- 1/28/07: shaky (Lorazepam?)
- 1/29/07: dex, skip in logical cognize
- fixate on chore
- 2/14/07: random aches & stiffness
- 2/20/07: balloon-headed
- 2/26/07: Thal shakes

Kato.

Gp A infusion changes: made June 2 '08

June 16 apptmt: ⑧ instead 7:30

July: ⑧ AM July 14 - instead 16th

Aug: ⑧ AM Aug 12 - instead 15th

325-3109

Dr. Ginsberg, 31 Jan. '08:

Again he was pleased with my blood-test results, in the exact words Carol took down:
"We have a very good trend."

Specifically, he viewed the monoclonal protein reading of 40 as "tiny," especially given that the count was 1623 back at the point where he became alarmed enough to launch me into the stem cell infusion. I wish the trace had not been measurable at all, as on the May and October immunofixation tests last year, but he interprets this as a trendline of readings so "tiny" (Carol noted he used the word repeatedly) as being hard to quantify. He said "we know there's something there," but it's been there these 7 years. (Today did mark 7 years and one day since Dr. Kato's phone call that she was referring me to Dr. G.)

The urine protein reading was 1316, down from 4960 back at the point of alarm.

My white cell count, somewhat low, has always been on the low side. Platelets count was good, he said, and hematorcrit normal.

The calcium and creatinine readings, regarding the kidneys, he says were okay.

Forgot to ask him about immunizations; will e-mail the question.

All in all, so far so good; next appointment at end of May.

Stacy Kiyatse / Infection 326-2645

- tetanus

- after

- In Visit summaries

scroll to bottom

to My letter

- patient



FINANCIAL PAYMENT AGREEMENT
ASSIGNMENT OF BENEFITS
(For Payment Arrangements 3 Months or Less / GHC Enrollees Only)

I hereby irrevocably assign to Group Health Cooperative any benefits due me under the terms of any insurance policy or policies, or otherwise, and/or Titles XVIII or XIX of the social Security Act that may cover my hospitalization, or disability, for medical services and hospitalization, but not to exceed Group Health's regular charges. It is further agreed that any credit balance resulting from consumer payment may be applied to any other accounts owed to GHC by the insured or beneficiaries covered through the insured.

I agree, whether signing as Agent, Patient, Guarantor or Legal Guardian, that in consideration of services to be rendered by Group Health Cooperative (GHC), I hereby obligate myself to pay GHC in accordance with the regular rates and terms of GHC. I understand that I am financially responsible for charges declined by, or not otherwise covered by, any other insurance benefits, and I agree to abide by GHC's payment policies and guidelines, including the payment arrangement structure below:

Patient Name and GHC consumer number: Ivan C Joig

Service provided and estimated cost: \$79.00

I agree to pay the amount of \$ 7, as a down payment for the above services. I agree to pay \$ 7 per month for 2 months until the balance is paid in full.

I understand that there may be additional costs/charges not noted in the estimate. Furthermore I understand that should my financial situation change, and I am unable to meet the agreed upon payment arrangements, I may be considered to make extended payment arrangements. I understand that if extended payment arrangements, at Group Health's discretion are required, a 12% annual interest rate would be assessed.

I certify that the information given by me for payment under Titles XVIII or XIX of the Social Security Act is correct, and request that said payment of authorized benefits are made on my behalf. Should this account be referred to an attorney or agency for collection, I agree to pay reasonable attorney's fees and collection expenses, whether or not a law suit is filed.

Signature x Ivan Dory Date 11 April 2008
(Of parent or guardian if patient is under 18)

ORIGINAL-PFS COLLECTIONS

COPY-PATIENT

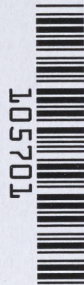
45221 (10/05)

*patient's doctor
Ordered
Polio vaccine (medically
will not collect payment + necessary)
now, however pt is aware he maybe billed fair*

26 MAR 2008

Ivan C Doig
17277 15TH AVE NW
SEATTLE WA 98177

Consumer: 00215848
Lab ID: 09320577



Here are the results of the lab tests STEVEN S GINSBERG MD ordered for you on MARCH 12 2008 at Northgate Medical Center Laboratory.

Dr. GINSBERG has reviewed these results. You will be contacted if a change in your treatment plan is necessary. We've also included test reference ranges as a guide to results that would be expected in a general population. These ranges are not personalized but only a general guide. Dr. GINSBERG may have different ranges for you.

You may check these results online, as part of your secure online medical record. (You must register with MyGroupHealth at www.ghc.org and then 'upgrade' your account. Follow instructions on the site.)

Do you already check your results online and prefer that? Go to your online Lab & Test Results area and click on the 'stop paper version' link. Also use that email form to resume receiving the mail version if you change your mind.

Component	Result Values	Reference Ranges	Units
TETANUS and DIPHTHERIA AB			
DIPHTHERIA ANTIBODY	L 0.04	0.11 - 10	IU/ML
TETANUS ANTIBODY	0.27	0.11 - 100	IU/ML
Antibody concentrations of greater than 0.10 IU/mL are considered protective.			
Timing of AB test? Single sample, protection status			
POLIOVIRUS			
POLIOVIRUS TYPE 1	H 10	0 - 9.9	TITER
POLIOVIRUS TYPE 2	H 10	0 - 9.9	TITER
POLIOVIRUS TYPE 3	LESS THAN 10	0 - 9.9	TITER
The presence of poliovirus antibodies may represent prior immunization or acute infection. The clinical significance of and the criteria for interpretation of results may require consultation with an Infectious Disease Specialist.			
HEPATITIS B SURFACE ANTIBODY			
HepBsAb	NEGATIVE		

We're pleased to have this opportunity to serve you.

Laboratory ID: 09320577

(Page 1 of 2)

26 MAR 2008 01:55

Group Health Cooperative Laboratory Services

RE: immunizations

To: Ivan C Doig

From: LYNN FLAHERTY, RN

Received: 3/10/08 3:10 PM

Hi Ivan

The first step is to get blood work to check your titres. I will put in the orders and you can get the lab done at Northgate. Once those results are in we can start the series of immunizations, which can be done at Northgate. WoW!! Maybe a movie option in your future. Good for you.

LYNN FLAHERTY, RN

----- Message -----

From: DOIG,IVAN C

Sent: 3/9/2008 6:51 AM

To: Office of Steven Ginsberg, MD

Subject: immunizations

Dr. Ginsberg, hi--In the first week in April it'll be a year since my stem cell procedure, and I believe you said I should be re-immunized then for practically everything. Will you set that up, and can I do it all at Northgate?

All is well here, I'm feeling fine and working with a lot of energy. Professional life is perking, the would-be movie guys just renewed their option on The Whistling Season--whether they'll ever actually film it, there's no predicting.

I hope you're thriving--see you at the end of May. Best, Ivan

Dr. Ginsberg, 10 Oct. '07:

He was pleased with my blood-test results, two in particular:

-- the hematocrit reading (anemia) has risen to 39; it was a reading down in the mid- or lower 30s that alerted Dr. Kato to what became the MGUS diagnosis, 7 years back.

-- the urine protein reading (kidneys) I think was 1590, down from nearly 4600 a year ago when the protein spike alarmed Dr. G.

The monoclonal protein reading still shows as officially zero, or as C took down his exact quote, "at the border of invisibility." Which is to say, the most refined test shows a trace, unmeasurable, but present. For now at least, he showed no concern over it.

My next session with him is Jan. 31; he said these can be on a 3-to-4-month basis, and I will work at getting them to 4, i.e. three times a year. He said in April, anniversary of the transplant, I'll need tests to see what inoculations I need for all the childhood stuff--chicken pox etc.--that the transplant wiped out immunity to. Told me not to bother with flu shot this year, but Carol should get one.

² Hanson
Dennis, Oct. 16 '07

- mite routine /
- Zomeda: strengthen bones
- prednisone every other day
- .3 spike
- no transplant in near future; Reulinid
on Thal.
- no siblings mated
(1 - 2 skd)

Your Messages

Use this form to send a message about **non-urgent** health concerns to your health care team or the Consulting Nurse Service. You'll get a confidential reply in your MyGroupHealth message inbox, usually by the end of the next business day.

Want an e-mail notice when a message arrives in your MyGroupHealth inbox? If so, we need your e-mail address: Please [update your profile](#) before typing your message.

Time limit: If you start to write a message but don't send it within 30 minutes, you will be automatically logged out. The message will be lost and you will need to start over. This is a security measure.

**This communication will become part of the medical record for IVAN C DOIG.
Use this form ONLY for messages about the health of this person.**

From: Ivan C Doig

To the office of: Steven Ginsberg, MD

Subject: resume acyclovir or not

Dr.Ginsberg, hi there--I'm doing dandy, working at full speed etc. Just to make sure I'd doing what I'm supposed to, I figured I'd check in with you now that I've seen Dr. Searce in neurology about my nuisance of neuropathy in the feet. He figures this is delayed reaction to the thalidomide, and that I can go back to taking Acyclovir (although he says it can cause some tingling) if you deem it still a good idea against shingles. I took it from mid-April until Aug. 8' what do you think,

Maximum 5000 characters.

Your message will be answered as soon as possible, usually by the end of the next business day. If you have an urgent health concern or require a more immediate response, call your physician's office or the Consulting Nurse Service:

Western Washington: 206-901-2244, 253-596-3400, or toll-free 1-800-297-6877

Central Washington, Eastern Washington or North Idaho: 1-800-826-3620

Please observe the following guidelines when using electronic communication:

- Do not use electronic communication for urgent matters. Normal turnaround time is 24 hours.
- Remember that documentation of the electronic communication may become a part of your medical record.

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From: Ivan C Doig

To the office of:

Subject:

Dr. Kato, hi again--Thanks for the quick referral to Dr. Searce in neurology. He clarified matters a lot, concluding that my foot numbness is likely a delayed reaction to Thalidomide and that it might go away in six months or more. So I feel better able to deal with it, knowing that.

No need to respond, just wanted to catch you up--I hope you have something nice planned for the weekend, it looks like a great one. All best--Ivan.

Maximum 5000 characters.

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RE: stem cell transplant result

To: Ivan C Doig

From: PATRICIA KATO, MD

Received: 6/21/07 8:51 AM

Dear Ivan,

Congratulations! This is wonderful news. I must say that your positive attitude throughout this whole ordeal has been admirable. Although there is no way to measure, I believe it makes a significant impact on outcome.

Best wishes and happy birthday!

Pat Kato

----- Message -----

From: DOIG,IVAN C

Sent: 6/20/2007 8:55 AM

To: Office of PATRICIA KATO, MD

Subject: stem cell transplant result

Dr. Kato, hi--Just wanted to share yesterday's good news from meeting with Dr. Ginsberg. For second month in a row, my blood and urine tests show zero monoclonal protein. Dr. G called my stem cell transplant result "remarkable," decreed no tandem transplant needed, turned me loose until he checks me over again at the end of September. I'm feeling great, regained normal energy a couple of weeks ago. (The only thing still missing is some hair and beard.) As Carol says, now I can have a very happy 68th birthday a week from now.

Best,

Ivan Doig

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Use this form ONLY for messages about the health of this person.**

From: Ivan C Doig

To the office of: PATRICIA KATO, MD -PCP-

Subject: stem cell transplant result

Dr. Kato, hi--Just wanted to share yesterday's good news from meeting with Dr. Ginsberg. For second month in a row, my blood and urine tests show zero monoclonal protein. Dr. G called my stem cell transplant result "remarkable," decreed no tandem transplant needed, turned me loose until he checks me over again at the end of September. I'm feeling great, regained normal energy a couple of weeks ago. (The only thing still missing is some hair and beard.) As Carol says, now I can have a very happy 68th birthday a week from now.

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Dr. Ginsberg, 15 May '07:

My current condition:

--Stamina has increased steadily, although I'm not 100% yet. *1-3 mo.*

--Sleep pattern is not as wretched as it was, but it's still choppy; more like a series of naps through the night, usually interrupted three times by need to urinate. Is there anything I can do to get decent nights' sleep without being dependent on Temazepam? *+ activity*

--Quite a bit of the time I'm bothered by a tightness and nagging discomfort down the back of the right leg. This has been recurrent in the past, connected with a tipped disk, but all the hospital-bed time and lack of usual exercise seems to have aggravated it. Is this a physical therapy problem, or is there some other way to alleviate it? *- legant vs in spine*

--This is new: if I get up too quickly from kneeling, in garden work or from doing stretching exercises, I become light-headed and almost faint. */ dehydration / fluids*

Prescription refill needed: Acyclovir *do by phone?*

--And if the groshong has to stay in me, I need more sodium cl. .9% 5 ml syringes for flushing the catheter. Also more paper tape to hold the catheter tubes in place.

If test results are okay, when can groshong be taken out?

If there's another round of chemo and stem cell transplant, how soon can it be done?

--By September, I'm scheduled to become a public person again. There's a major award ceremony, a lucrative speech date, and a couple of important promotional events for my last book.

--Hair & beard; it's been a month now since it began falling out--likely to start coming back soon? Does it grow back at normal pace when it does?

- maintenance Thalidomide: from now on?

9 who had test / if no problem, home monitor

5 who /

to appointment / June 14~~th~~ 19

GUARANTOR ID/SUBSCRIBER ID	STATEMENT DATE	AMOUNT DUE	DATE DUE
215847	04/30/07	\$100.00	05/20/07

ACCOUNT NUMBER	TRANSACTION DATE	PATIENT NAME	ACCOUNT ACTIVITY	AMOUNT
47389056		Ivan	Physician Based Services	
	04/03/07	DOIG	FLUOR GID CTR VAD PLMT R	46.00
	04/03/07		US VASCULAR ACCESS	23.00
	04/03/07		TUN CEN VEN W/O >5YR	1,880.00
	04/16/07		COVERED BY GHC	-1,849.00
Payment in full should be made by the statement due date.				

For additional information,
please refer to back of bill.



GroupHealth

For questions, please call Customer Service
between 8 a.m. - 6 p.m. Monday - Friday
or between 9 a.m. - 2 p.m. Saturday 1-888-901-4636
TTY/TTD relay service: 711 or 1-800-833-6388
or E-mail us through www.ghc.org/customerservice

TOTAL DUE

\$100.00

#3616
5-10-07

Pay by check, money order, or credit card

Checks and money orders should be made payable to Group Health Cooperative. To ensure proper credit to your account, please list on the face of your check the account number(s) from the left column of the bill. If you do not list the accounts, payment will be posted to the oldest outstanding balance. Please enclose the upper section of this statement with your payment and retain the lower section for your records.

We also accept MasterCard, Discover Card, and VISA. To submit credit card payment by mail, please complete the box in the upper right hand corner of the front page of this statement. Or pay by phone at 206-901-7103 or 1-800-442-4014 (select option 2).

Your account responsibility

Group Health Cooperative bills your insurance as a courtesy. However, it is your responsibility to see that your account is paid in full. Please remember that health insurance coverage varies and not all services are covered. Please check your contract for your specific benefits. If an insurer makes payment for our services directly to you, please endorse the check payable to Group Health Cooperative and forward in the enclosed envelope.

If you do not have insurance or if there is a balance remaining, this amount is due upon receipt of your first statement. Please remember that copayments are due at the time of service. You may pay by check, MasterCard, Discover Card, or VISA at all Group Health locations.

Definition of key terms

- Account numbers - Used to identify each visit or service
- Guarantor ID/Subscriber ID - Used to identify who has agreed by contract to pay the bill
- Balance forward - Reflects amount still due following a previous statement if not fully paid
- Account activity - Includes services, payments and adjustments
- Transaction dates - Date of visit or service, payment, and/or adjustment
- Contractual discount or adjustment - Amount insurance or provider has agreed not to charge
- Guarantor payment - Payments made by the guarantor/subscriber for services
- Insurance payment - Payments made from an insurance company other than Group Health



PATIENT FINANCIAL SERVICES
PO BOX 34365
SEATTLE, WA 98124-1365

Th: e-mail / to come in?

Dr. Ginsberg, 21 April '07:

My current condition:

--diarrhea; not really bothersome, sort of a polite kind. ⑥ Loperamide Hydrochloride tablets left. 1 wk?

--mouth almost OK; palate above tongue still feels a bit 'scalded.'

--eating OK, although I haven't tried steak or spicy food etc. yet.

--fatigue: still have some. (but 1/2 hr walk this morn) 6-12 wks

--sleep: not very good. 4 hrs last night w/ Tamezapam, plus nap; 2 hrs night before without sleeping pills.

- drippy nose

When might each of these be normal?

→ Any prescriptions needed today? - prevent shingles 1/3 times/day 4 mos.

Next week's schedule (blood draws?)

old nose /

When can the catheter come out? 4-6 wks

When do the catheter stitches come out? When does dressing get changed?

When can I work in my garden? (Is digging in dirt OK, w/ sterile plastic gloves on?)

When can I eat food from our garden--lettuce, radishes, spinach?

When can I eat rare beef, i.e. cheeseburger off our own grill?

wt: 153 ideal - try to hold it there, or do you want me to keep fattening up w/ smoothies etc.?

When can I have a drink before dinner? ... be with people?

Hair loss:

--is my beard a goner (it has already shed a lot) and should I shave it off and start over? spotty

--how long might it take for new growth of hair/beard to begin? wks

153.8 104/60 (why so low?)

e-mail
Dr. Ginsberg
May bld
draws
needed (if
is that all?)

Th: e-mail / to come in?

Dr. Ginsberg, 21 April '07:

My current condition:

--diarrhea; not really bothersome, sort of a polite kind. (6) Loperamide Hydrochloride tablets left. 1 wk?

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old man /

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--is my beard a goner (it has already shed a lot) and should I shave it off and start over? spotty

--how long might it take for new growth of hair/beard to begin? wks

153.8 104/60 (why so low?)

4-6 wks re-evaln protein

- w/ protein, hip
- drug for remission

2nd transplant (tandem)

May ^{1st} ~~1st~~ ^{wa} - re-eval'n

whole infusion center

- mitox Thalid, 50 or 100?

0 protein

0 bone marrow cells

RE: next blood draw

To: Ivan C Doig

From: LYNN FLAHERTY, RN

Received: 4/23/07 12:13 PM

Hi Ivan

Yes you should get blood counts done the week before. You can certainly go to Northgate, but I don't think they will draw from your catheter there. If you want the nurses here to do it, you can just call Nick and get on the schedule for a blood draw. Yes you can re start the glucosamine. I'm glad you did so well. Talk with you soon.

LYNN FLAHERTY, RN

----- Message -----

From: DOIG,IVAN C

Sent: 4/22/2007 9:54 AM

To: Office of STEVEN GINSBERG, MD

Subject: next blood draw

Dr. G and Lynn, hi--Our next appointment is scheduled for May 15.

To make sure I understand the preliminaries to that:

--Am I right that I should get a blood draw the week before? if so, I'd like to do it at Northgate if possible.

--I don't see anything on the schedule at the infusion center or anywhere else before then: correct? (Carol and I are going to try flush the catheter weekly ourselves.)

Next topic: can I resume taking glucosamine/chondroitin for my achy arthroscoped knees? I know I'd have to quit again if there'll be a tandem transplant, but on the chance there won't be I'd get a headstart now (it takes about a month for glucosamine to have any effect on me, but then it seems to work) if I could.

Best, Ivan

Dr. G., Apr 20 '07.

g.m.: p. 27, catheter 6-8 wks after transplant (i.e., May 10-24?)

Bathing instructions: after 3 wks (Apr. 24) dressing not needed (?)

g.m.: p. 30, 1st mo: twice w/ly exams

2d & 3d mo: bld draws every 2 wks

"eventually": every 3-4 wks

1st 90-120 days: gtrly dr exams

24 mos: gtrly exams

g.m.: p. 39, follow diet 1st 3 mo.

g.m.: p. 58, fatigue 3-6 mo.

g.m.: p. 60, sun & skin; p. 61, plenty of fluid

g.m.: p. 62 shingles w/b yr in 40-50% cases

my sense of taste a bit off

taking in a lot of calories (shakes 800 cal./each?)

ideal wt/max wt?

diarrhea: Lopramide (6 pills left)

sleep: Apr. 19, 4 hrs, feel gd

roof of mouth: a bit scalded

can I have a drink before dinner?

chemo thlet: p. 55, tension & release x crier

p. 56, rhythmic breathing

gardening: OK w/ sterile gloves? (no digging)

- eat salads & other garden fare?

Next week's shed (Lignin?)

Any prescriptions needed? (anti-diarrhea ^{which also} is o/c, I think)

Catheter: When can it be removed? Also, stitches?

When will mouth + digestive system be normal?

Also, end of diarrhea. ("Stem cell" p. 52 - up to 2 mo.)
→ Cf. 59

When can you walk in your garden / eat lettuce +
rare beef / go anywhere in crowd?

How long does it take for new growth of hair to
begin?

Dr. Ginsberg, 30 March '07:

Catheter and chemo schedule, Tuesday, April 3:

--no breakfast; coffee and/or clear juice to 5 a.m (source: Jessica, Radiology).

7 a.m., check in at Infusion Center.

8 a.m., someone from Radiology will fetch me for catheter (Graschang) process.

9, should be done; I'll be observed until 10:30 for possible "tenderness."

Chemo, 60-90 min. worth, will be done after that; we should figure on at least half the day at Gp H. Take some food (banana & yogurt?) although they'll provide lunch.

Re-infusion, Thursday April 4:

8 a.m. infusion, 30 min. process according to Dr. G; 15 min. per stem cell bag, according to Paulette in her earlier briefing, and I must have 3 bags from the 3 days of collection. She also said "2 hours IV hydration before."

Then I'm watched for 4 hours. Will be in a room with bed and recliner; can read or work (revise Eiseley-Morris speech chunk for P-I piece?).

All in all, it looks as if we should figure on "most of the day," as Dr. G said, at Gp H. Take some food (banana & yogurt?) although they'll provide lunch. I'll have the "garlic" taste in my mouth from the DMSO preservative; Paulette me orange wedges might help.

told

Catheter: because of my bad back, I have to sleep on my right side--can catheter placement allow for that?

--Yes; placement is negotiable. (It is a chest placement.)

If there are any mitigating medications--anti-nausea or anti-diarrhea or whatever--I'd like to pick them up at the pharmacy today, rather than face the pharmacy during any of the chemo procedure.

--None; this will be done with infusions during chemo process Mon./Tues.

Are Temazepam for sleeping and Lorazepam for calming down okay during all this?

--Yes.

Masks against possible infection: worth doing when I come here for appointments, or in any vegetable gardening I might do? Does the pharmacy stock them?

--Not necessary. But I must not dig in the dirt the first few weeks after chemo. (I'll ask again later in the recuperation.)

In case I decide I need hospitalization at night or on a weekend, what are the exact specifics of getting admitted to Virginia Mason? Will it be a private room? If not, what does it take for me to get one?

--It's a private room.

-- I ought to be "okay"--i.e., no hospitalization--to Mon./Tues, April 9-10.

--If I do need to go to the hospital, **the Virginia Mason emergency room** is at **Spring St. and Terry Ave.**

If I'm recuperating at home, do Carol and I do any special evaluation on Fridays whether I can make it through the weekend at home or ought to go to the hospital?

--Group Health daily evaluations should handle this.

After the infusion and the reaction, how soon might I begin to feel better?

--first two weeks, I should show improvement.

--next four weeks, I should regain energy.

--in next six weeks-three months, I should reach the point of feeling "normal." Dr. G. thinks my general good health should let me "bounce back" fairly rapidly.

Dr. G. said I'll be taking antibiotic pills against shingles etc. for 4-6 months.

He had no concern about any of the readings in my March 26 blood test; said the 1.2 protein reading, "slowly rising" from last time, is "trivial" compared to the decline achieved during the drug regimen.

Wt: 153 Bld pressure: 120/70

Thursday, 15 March '07:

Paulette called just before 5 p.m. to say I was done with stem cell collection. Total was 8 "point something," she did not have result at hand. She said my readings--white cell count primarily, I guess--were falling, so Dr. G. has said "fine" about the result (even though it's short of the goal of "ten" which would allow for two full-count transplants. The nurse Phil in the Hutchinson apheresis room told me that if necessary transplants can be done with a little as a count of two, e.g. two million stem cells per kilo of body weight).

The next phase:

March 26, Northgate blood tests

March 30, 10 a.m., appointment with Dr. G. Also a session with Lynn about the transplant process.

April 2-3, chemotherapy.

April 5, the transplant.

I will need a catheter before the chemo, and Lynn will call me about that.

call Paulette:

finished 8.

met 'm

Dr. G. said 'join'

- next phase:

2 days Apr. 283

+ transplant 5th

→ Mar 30, @ 10 AM Dr. G.

- Negative blood tests Mar 26

- Lynn: meet w/ o. transplant

- catheter: Lynn to call about

215848

- pharmacy: C pick up? GpH Central arranged... -
- 5 CSF / ~~over~~ Neupogen avbl?
 - if not, how can ~~it~~ it be arranged

300 mcg / 1 mL

- 4mg / indiv'l needles
same side upper & lower
- no refu'g

2 liter bottle for discard / cap on bottle
dispose @ lab

-

March 5 '07 questions for Dr. Ginsberg:

3 atts SPE

About 4 days ago (Friday, March 2) my body began to seem closer to normal, without the twinges (such as the calf muscle pull and a groin pull) and with the constipation easing off. The few lingering concerns I have as of now:

- my energy is still lagging; I feel maybe 85% of normal energy level.
- I'm tremulous for the first 3-4 hours after I get up and don't feel mentally sharp during that time
- ~~I feel cold~~
- Some continued flatulence, which maybe is decreasing.
- ~~urinating more than usual~~
- Some hand cramping, not as bad as it was the last week or so of Thalidomide but still occasional.

*** Specific schedule from here?

(no later than 1700)

3 days
urgent
care

Sat. - injection

1000 - Sun.

1700 - Mon: bld test (Cay H, early morn)

- Mon or Tues: stem cell collection

re-infusion 1 wk of 19th/26th

5 days

--chemo or no?

- negotiable (cyclophosphate?)

- injections on a Sat.

--Neupogen injections anyway?

2 wks: clear sched

3-4 wks O/R, a'wait fatigued
mo to 6 wks

Methylalam is done

2 days / 4-10 days

--Likely side effects from any of this? (Energy level? Hole up at home against infection?)

***What shape am I likely to be in a week or so before re-Infusion? (i.e., March 26-27 when Becky maybe in town.) - able to go out to dinner

Nov. 9 '06:

Things to consider doing:

--look at the myeloma website

--get fluent on-line with Grp Health; I probably should begin communicating with Dr. G by e-mail, as writing is my strength and taking in full medical info in his office is not. Consider a new computer w/ on-line capacity.

after Thanksgiving --adapt the guest bedroom in case I need it more often (sleeplessness and other side effects possible in any treatment involving dexamethasone). Get pillows to match my usual ones and consider new bed & mattress and possibly a small chest of drawers (or use C's little desk that is already in the room if it can be made workable).

--clear away some usual late-year chores now, to allow for time-consuming medical appointments on into Dec. and likely Jan.:

--~~contributions~~ list

--Xmas letter

--Sched C expenses

--desk calendars

~~Xmas shopping for C (Thurs. 16th)~~

physical w/ Kato?
keep watch on prostate?

financial:
- move E-trade to Dain
(in new yr)
- start my Soc. Sec.?
(when medical prognosis
becomes clearer)

Nov. 9 '06:

Things to consider doing:

--look at the myeloma website

--get fluent on-line with Grp Health; I probably should begin communicating with Dr. G by e-mail, as writing is my strength and taking in full medical info in his office is not. Consider a new computer w/ on-line capacity.

*after
Thanksgiving*

--adapt the guest bedroom in case I need it more often (sleeplessness and other side effects possible in any treatment involving dexamethasone). Get pillows to match my usual ones and consider new bed & mattress and possibly a small chest of drawers (or use C's little desk that is already in the room if it can be made workable).

--clear away some usual late-year chores now, to allow for time-consuming medical appointments on into Dec. and likely Jan.:

~~--contributions list~~

--Xmas letter

--Sched C expenses

--desk calendars

~~--Xmas shopping for C (Thurs. 16th)~~

*physical w/ Kato?
keep watch on prostate?*

March 5 '07: looking ahead

Starting this month, I think I am likely to be much more of a medical patient, i.e with bodily discomforts that will need tending and frequent medical appointments.

Dr.Ginsberg's calendar estimate at our last appointment with him was mid-March for stem cell collection, which as I savvy it has to have at least 4 days of Neupogen injections beforehand (and some afterward), then 2-3 weeks to re-infusion in early April.

The body situation:

- possible sore chest after catheter is put in.
- possible bone pain from Neupogen injections.
- garlic odor from stem cell preservative for up to a week after re-infusion.

The possible medical appointments:

- twice a week blood tests during Neupogen injections, I hope at Northgate.
- at least two 2-4 hour stem cell collections at the Hutchinson on successive days; dizziness etc. is possible, Carol will need to drive me.

28 Feb/ '07: 60 hrs beyond Thal now, and to my surprise/dismay this morn, I am somewhat shaky, enough so that C is going to drive me to Gp H to deliver the urine sample jug. I think the shakes likely come from the sleeping pills that I resorted to last night, so I wouldn't have to get up half a dozen times to pee in the jug. (As it was, 3 times, and the 2nd one topped off the damnable jug.) I am fairly clear-headed, have made a schedule for the day etc. My next task is going to have to be getting adequate sleep without pills; videos in the evening, maybe.

All in all, though, as C said at b'fast, when I hand in the urine jug, I am free at last of the regimen that began Jan. 1. Until, of course, the March 5 session when Dr. G plots out the stem cell schedule.

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**This communication will become part of the medical record for IVAN C DOIG.
Use this form ONLY for messages about the health of this person.**

From: Ivan C Doig

To the office of: STEVEN GINSBERG, MD

Subject: sore calf result

Lynn--On Friday Dr. Madwed at Northgate took a look at my painful left calf and ruled it not a blood clot but a muscle pull--i.e., no engorgement, flesh was good and loose, and it twinged like a muscle pull when she manipulated my foot. Stretching and ice-packing have relieved it a lot.

Today I took my last dexamethasone dose, and I finish with Thalidomide next Sunday, the 25th.

Getting there. Will have blood tests done at Northgate

Maximum 5000 characters.

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on . 26th & on . 27th will do the 24-hr
urine test Dr. E wants. See you all
at . March 5 apptmt. Best wishes.

Blood draw weekly - PT warfarin

January 2007

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1 thalidomide daily	2	3	4	5 b/d draw N'gate	6
	Dex	Dex	Dex	Dex		
7	8	9	10	11	12 b/d draw N'gate	13
		Dex	Dex	Dex	Dex	
14	15	16	17	18	19 B/d draw N'gate	20
			Dex	Dex	Dex	Dex
21	22	23	24	25	26 get labs N'gate	27
		call Lynn 206 326 2645 - Thal. phone survey for renewal of thalid.	Dex			
	week off					
28	29 Dr. Ginsburg visit - 1:10pm	30	31			
	start dex again					

do labs
even
earlier
in week?

Blood draw weekly - PT
warfarin

January 2007

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1 thalidomide daily	2	3	4	5 b/d draw N'gate	6
	Dex	Dex	Dex	Dex		
7	8	9	10	11	12 bld draw N'gate	13
		Dex	Dex	Dex	Dex	
14	15	16	17	18	19 Bld draw N'gate	20
			Dex	Dex	Dex	Dex
21	22	23	24	25	26 get labs N'gate	27
		call Lynn 206 326 2645 - Thal. phone sunday for renewal of thalid. week off from Dex	Dex			
28	29 Dr. Ginsburg visit - 1:10pm	30	31			
	start dex again					

Feb. 16 '07: Dr. Madwed at N'Gate about sore calf

my written report to her:

Monday morning when I got up, my left calf was very painful, centered along the interior half of the big muscle, starting about six inches below the back of the knee.

It stayed that way, particularly stressful and stiff the first three or so hours of each day, until this morning. Right now it feels considerably better, perhaps because I iced it for a long time last evening and I took sleeping pills--to counteract the dexamethasone feeling of heightened alertness--which let me sleep solidly through the night without having to get up to go to the bathroom. The other nights, the bathroom visits were treacherous, with the left leg difficult to stand on and navigate, and I had to be exceedingly careful not to fall.

The remedies I've tried so far:

--a couple of sessions with a heating pad did not seem to help.

--icing seemed to help a little, although none of my earlier sessions produced nearly as much relief as last night's extended use of ice pack seems to have.

--Carol and I walk about two miles a day as part of our exercise. I gingerly tried the leg on these outings, and found that it was stiff but bearable when I started out and by about three-quarters of the way through the distance it had loosened up a lot and felt better. It would then stiffen up again during the day and get as bad as ever overnight.

--I do a mild set of stretching exercises at the end of each workday, and found the calf would tolerate these if I was careful.

Dr. M:

--There's no significant swelling and the flesh is nice and loose--i.e., no sign of blood engorgement; also the calf twinged as it would on a muscle pull when she flexed my foot toward my shin. So, no blood clot, she concludes.

--Try heat or ice, whichever works. (I'll stick with ice, which seems to.) I can also do mild stretching exercises, such as the leaning-against-the-wall one I start with and one in which I pull the top of the foot toward me with a doubled towel. At night, I could sleep with a hiking boot on (wrapped in plastic bag) to keep the foot at a 90-degree angle, although I don't think it'll come to that.

--I may be slow to heal while I'm on dexamethasone.

--Don't hesitate to come back in if I have any suspicion of a blood clot.

RE: sore calf

To: Ivan C Doig

From: LYNN FLAHERTY, RN

Received: 2/15/07 3:09 PM

Hi Ivan

I am thinking you should make an appt with your primary physician to have your leg looked at. It is common for blood clot formation when on thalidomide. The signs are usually pain, and sometimes redness and swelling. If a clot can be ruled out ,then other measures for comfort on warm compresses to leg, elevation, and mild leg exercises.

LYNN FLAHERTY, RN

----- Message -----

From: DOIG,IVAN C

Sent: 2/15/2007 9:05 AM

To: Office of STEVEN GINSBERG, MD

Subject: sore calf

Lynn & Dr. G--The past couple of days I've had a severe cramp in my left calf. It not only hurts a lot but it's so stiff that it's treacherous at night when I have to get up to go to the bathroom. Any advice on some way to ease it?

I'm on day one of the final dex pulse, and I finish with Thalidomide on the 25th. Will have blood tests done on the 26th, and do the 24-hr urine test on the 27th, preparatory to my appointment with Dr. G on March 5. Except for this highly aggravating pain in the calf muscle I'm doing okay, I think.

Best. --Ivan

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After Visit Summary

Ivan C Doig (MRN 00215848)

Visit and Patient Information

Visit Information	<u>Date</u>	<u>Time</u>	<u>Department</u>	<u>Provider</u>
	01/29/2007	1:10 PM	CSC ONCOLOGY	STEVEN GINSBERG, MD

Vitals	<u>BP</u>	<u>Wt</u>
	110/62	155 lbs 3.2 oz (70.4kg)

Instructions and Follow-Up

Patient

Instructions Blood and urine testing about a week before next visit with STEVEN GINSBERG, MD

Visit Follow-Up	<u>Follow-Up</u>	<u>Return For</u>
	Return in about 5 weeks (around 3/5/2007) for follow-up.	follow-up

Orders

Ordered	<u>Prescription</u>	<u>Disp</u>	<u>Refills</u>	<u>Start</u>	<u>End</u>
	THALIDOMIDE (THALOMID) 200 MG ORAL CAP	28	0/0	1/29/2007	3/28/2007
	Sig - Route : Take one capsule daily at bedtime. Authorization # 1082071. - ORAL				
	Non-formulary Exception Code : B. Patient meets criteria for use				
	VITAMIN B-6 50 MG ORAL TAB	200	0/0	1/29/2007	6/8/2007
	Sig : TAKE TWO TABLETS DAILY				
	WARFARIN 1 MG ORAL TAB	30	2/2	1/29/2007	7/28/2007
	Sig - Route : TAKE ONE TABLET ONCE A DAY - ORAL				
	DOCUSATE SODIUM 250 MG ORAL CAP	100	0/0	1/29/2007	3/30/2007
	Sig : 1 daily				
	SENNA 8.6 MG ORAL TAB	100	0/0	1/29/2007	3/30/2007
	Sig : 1 daily				
	DEXAMETHASONE 4 MG ORAL TAB	120	2/2	1/29/2007	3/28/2007
	Sig - Route : 10 PILLS DAILY DAYS 1-4, 9-12, 17-20; REPEAT EVERY 28 DAYS - ORAL				

Order Summary Orders
ELECTROPHORESIS-URINE PROTEIN (24 HR PREFERRED) (* [84165.004])

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Pharmacy Dispensing List

Print Date 01/29/07

Dispensed at CENTRAL MED CTR SOUTH on 01/29/07 at 13:57 by 029847
Federal Tax ID: 91-0511770 Phone: 1.888.901.4636 NCPDP Number: 4906838

PATIENT: DOIG, IVAN (MEMBER# 00215848)
#####

Prescription Date Of NDC Days Patient
Number Service Qty Supply Price Charge Charge Reason

0257-3395-904 01/25/07 28 28 3,645.00 30.00 Cost Share
THALIDOMIDE 200 MG CAPS
Prescriber: GINSBERG STE

0297-5725-301 01/29/07 1 50 3.50 3.50 Not Covered
PYRIDOXINE 50 MG BOT (UPC 79854-20030)
Prescriber: GINSBERG, S S

0297-5731-101 01/29/07 100 100 4.80 4.80 Not Covered
DOCUSATE SODIUM 250 MG CAPS (NDC 54629-601-01)
Prescriber: GINSBERG, S S

01/29/07

0297-5733-401 01/29/07 100 100 4.90 4.90 Not Covered
SENNA CONC TABS (NDC 0182-1093-01)
Prescriber: GINSBERG, S S

3546-6045-701 01/29/07 30 30 13.00 10.00 Cost Share
WARFARIN 1 MG TABS (NDC 0555-0831-02)
Prescriber: GINSBERG, S S

3546-6054-801 01/29/07 120 28 27.10 10.00 Cost Share
DEXAMETHASONE 4 MG TABS (NDC 0054-4184-25)
Prescriber: GINSBERG, S S

Account 046026010 Charges: 63.20/Pre-payments: 63.20/Due: 0.00

Total Patient Charges 63.20/Pre-payments: 63.20*Due: 0.00*

The above item(s) have been charged to your bank card. This amount will appear on your statement as "Group Health Pharmacy."

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0.00

0.00*

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Use this form ONLY for messages about the health of this person.**

From: Ivan C Doig

To the office of: STEVEN GINSBERG, MD

Subject: Thalidomide prescription

Lynn & Dr. G--When I went to Northgate this morn for blood tests, the Temazepam you prescribed yesterday indeed was there but they were out of stock of Thalidomide. The pharmacy person worked her computer for a while and transferred that prescription back to Central, where she says I can pick it up on Monday. Thought I should alert you, to make sure the stuff is available according to the schedule you've set up.

See you Monday.

Maximum 5000 characters.

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RE: sore bottom

To: Ivan C Doig

From: LYNN FLAHERTY, RN

Received: 1/17/07 12:47 PM

Hi Ivan

Glad to hear you are not constipated. You can try sitz baths, which basically is just sitting in warm- hot water and putting some epsom salts into the water also is vey soothing. Anusol cream is fine or even something like shea butter Is good also.

LYNN FLAHERTY, RN

----- Message -----

From: DOIG,IVAN C

Sent: 1/17/2007 10:05 AM

To: Office of STEVEN GINSBERG, MD

Subject: sore bottom

Dr. G & Lynn--Starting last dex pulse in pretty good shape except for anal discomfort. When bowel movements finally kicked in on Sunday there were several, and my anus ended up distended and sore. I'm using aptly-named Anusol hemorrhoidal ointment on it; any further remedy to suggest?

Best regards.

--Ivan

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From: Ivan C Doig

To the office of: STEVEN GINSBERG, MD

Subject: sore bottom

1/17
Dr. G & Lynn--Starting last dex pulse in pretty good shape except for anal discomfort. When bowel movements finally kicked in on Sunday there were several, and my anus ended up distended and sore. I'm using aptly-named Anusol hemorrhoidal ointment on it; any further remedy to suggest?

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To: Ivan C Doig

From: LYNN FLAHERTY, RN

Subject: RE: Monday status of rash

Received: 1/8/07 12:49 PM

Hi Ivan

Glad to hear that the rash is diminishing and the BM's have commenced. It is probably best to keep up with the stool softener and laxative regime while on the thalidomide. As far as watching what you eat, i think things will balance out for you. Being on the dex is at first a bit of a shock to the body and it does increase your appetite. I think your awareness of this is the best thing and when you are off the dex your appetite will swing back to normal or less then normal as you will probably have a feeling of fullness. Anyway, glad things are progressing well and keep us posted.

LYNN FLAHERTY, RN

----- Message -----

From: DOIG,IVAN C

Sent: 1/8/2007 7:08 AM

To: Office of STEVEN GINSBERG, MD

Subject: Monday status of rash

Dr. G & Lynn--Rash diminished over the weekend to just a trace. And bowel movements commenced, although not much comes out. New question, weight: I put on 3 lbs last week. Throttled back some on calories over weekend, but how vigorous should I be about it--i.e., is this something temporary from dex, or had I better pay strict attention to not letting it pile on at this rate?

Onward to the 2nd dex pulse tomorrow.

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To: Ivan C Doig

From: STEVEN GINSBERG, MD

Subject: RE: how the rash looks

Received: 1/5/07 11:24 AM

Stay the course!!!

----- Message -----

From: DOIG,IVAN C

Sent: 1/5/2007 10:56 AM

To: Office of STEVEN GINSBERG, MD

Subject: how the rash looks

Without experience to go by, Carol and I think it does look acne-like: pink instead of reddish, blotchy and slightly raised, from pinhead-size to 2-3"-long trails. It's on maybe half my back, then mostly across my right shoulder, down and around. Doesn't look appreciably worse than earlier. Bought hydrocortisone cream while we were @ Northgate, haven't had to use it yet. Stay the course?

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Your Messages

[E-mail Health Care Team](#)[Message Inbox](#)[Sent Messages](#)[Back to Message List](#)**To:** Ivan C Doig**From:** STEVEN GINSBERG, MD**Subject:** RE: rash**Received:** 1/5/07 10:39 AM

Hi Ivan,

Acne-like rashes are very common with dexamethasone. Does it look acne-like? Hydrocortisone is OK to try. I think the cloudy head is also the dexamethasone.

Please let us know how things proceed.

Steve

----- Message -----

From: DOIG,IVAN C

Sent: 1/5/2007 7:30 AM

To: Office of STEVEN GINSBERG, MD

Subject: rash

Lynn and Dr G--Rash spread a lot overnight, from spinal area to shoulders and a bit around to top of my chest. Still no itch, but am getting hydrocortisone cream as precaution with weekend coming. What do you think, hang in there otherwise? The rash looks like hell but otherwise isn't bothering me yet.

-- Carol is driving me to Northgate this morn for 1st blood draw as soon as they open.

--Clearer-headed this morn than all day y'day, the dex wearing off, huh?

--Will start laxative/stool softener routine as soon as we're back from Northgate.

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To: Ivan C Doig

From: LYNN FLAHERTY, RN

Subject: RE: therapy side effects

Received: 1/4/07 2:32 PM

Hi Ivan

Thanks for the update. yes, I agree re start use of laxative and stool softener. Let us know about rash symptoms if they persist or get worse. Eucerin is fine to use for now, maybe some hydrocortisone over the counter cream if it starts to itch would be helpful.

LYNN FLAHERTY, RN

----- Message -----

From: DOIG,IVAN C

Sent: 1/4/2007 11:51 AM

To: Office of STEVEN GINSBERG, MD

Subject: therapy side effects

Dr G & Lynn--Rash appearing on my back. No itch (yet?)

Using Eucerin on it; adequate for now?

--Bowel movements lacking (plenteous gas, though). Got some stuff out y'day with fleet enema. Early as it is in therapy regimen, figured I'd resort to laxative/stool softener if nothing moves today; sound right?

Otherwise pretty much tolerating 1st phase Thal/dex OK.

A bit spacy 1st thing out of bed, but I get by with First Rule of Wingwalking: "Never leave hold of what you've got, until you've got hold of something else." Anyway, so far so good, I guess.

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March 5 '07 questions for Dr. Ginsberg:

About 4 days ago (Friday, March 2) my body began to seem closer to normal, without the twinges (such as the calf muscle pull and a groin pull) and with the constipation easing off. The few lingering concerns I have as of now:

--my energy is still lagging; I feel maybe 85% of normal energy level.

--I'm tremulous for the first 3-4 hours after I get up and don't feel mentally sharp during that time.

--I feel cold.

--Some continued flatulence, which maybe is decreasing.

--Some hand cramping, not as bad as it was the last week or so of Thalidomide but still occasional.

Dr. G. said all of those sound drug-related. In the course of this conversation, I cited the end of taking Thalidomide on Feb. 25th, which turned out to be contrary to his intention that I would stay on Thalidomide. Told him the two months' worth were all that were on the schedule given to me, and indeed Lynn or her fill-in made no mention of the re-ordering regimen that would have had to be done about Feb. 20th to continue. Quite quickly Dr. G. decided to let the situation stand, not get into re-starting the Thalidomide, and went instead to proceeding with the stem cell schedule:

Stem cell schedule:

As early as this Saturday, March 10, or no later than next, March 17, Neupogen injections are to begin; Saturday and Sunday, then on Monday, a particular blood test early in the morning at Capitol Hill to gauge things. Depending on that result, stem cell collection would begin Monday or Tuesday.

--Re-infusion would then be either the week of March 19 or March 26. He said to clear my schedule for 2 weeks afterward, I will be too wiped out to do much. At 3-4 weeks I should feel towards OK, although somewhat fatigued. A month to six weeks after that, I should feel normal.

--It turns out that there normally have been two chemotherapy applications in this process, and it is the first one, during stem cell collection, that has been called into question by a recent study. (It's not mentioned in the stem cell pamphlet given to me.) Dr. G. said that one is "negotiable," and when I said I would like to not have it, to spare my body as much as possible, he said OK. (C remarked afterward that he really wanted me to say that.) Thus I am still in for the Melphalan chemo at the time of re-infusion which likely will result in a hospital stay; likely two days at Virginia Mason, although it could be as much as 4-10 days.

This schedule is still in flux, as Dr. G. has to work it out with his Grp H team and also see if the days he wants will fit with the Hutchinson, where the stem cell collection is done. He or a nurse will call me when the schedule is settled.

It sounded as if there may be a preliminary trip to the Hutchinson for the staff there to see if my veins are OK for the collection process or whether I need a catheter. The collection ratio is 10 million cells per kilo of bodyweight, which I work out to be 680 million cells.

WT 151 Bed pressure 120/76

Jan. 28 questions for Dr. Ginsberg:

Shakiness (evidently from Thalidomide?) set in yesterday, continues today. OK?

Rash is recurring in one patch of my back and a bit on front of my shoulders. OK?

Some neuropathy in right foot, past week or so. OK?

My butt is quite sore sometimes; anything more to be done besides Anusol and sitz baths?

Lorezapam: I haven't used it, but is it pretty surely a calming influence?

Dr. G listened to all of the above, said I am really tolerating the Thal/dex very well:

--if foot numbness persists, I can cut back to Thal every other day.

--I can try K-Y, vaseline, soapy water or chamois butter for wiping my butt instead of toilet paper.

--Lorezapam will indeed calm me down if needed.

More vitally, the protein reading was dramatically down--.7 from 2.7--and he foresees one more set of Thal/dex for me instead of the two I expected. The schedule he anticipates is mid-March for stem cell collection, then 2-3 weeks to re-infusion in early April. He cited a recent article which calls into question the usefulness of chemo during the collection process, so he's thinking about skipping that with me; that would cut the overall collection process from 2 weeks to 5 days, and be easier on me.

My ProTime readings for Cumoudin have been fine, he says don't do any more.

He has taken Pamidronate out of the picture, saying it doesn't fit my case.

I am to have a 24-hr urine test before seeing him on March 5.

WT 155 bld pressure 110/62



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[E-mail Health Care Team](#)[Message Inbox](#)[Sent Messages](#)[Back to Message List](#)**To:** Ivan C Doig**From:** LYNN FLAHERTY, RN**Subject:** RE: reporting on 2nd dex pulse**Received:** 1/12/07 1:12 PM

HI

Thanks for the update! Things sound doable and I'm glad. Have a great weekend also and stay warm.

LYNN FLAHERTY, RN

----- Message -----

From: DOIG,IVAN C

Sent: 1/12/2007 7:48 AM

To: Office of STEVEN GINSBERG, MD

Subject: reporting on 2nd dex pulse

Dr, G & Lynn--pretty good week, less cloudy from dex.

--Rash persists on my chest from breast to base of neck and overnight light splotches came again along middle of back. May have been aggravated by coarse warm shirt I unthinkingly put on against cold weather; have switched to a softer one and am still hitting rash with hydrocortisone cream.

--Weight back to where I started.

--Bowel movements still irregular, but I'm coaxing something out at least every other day with 2-a-day laxative and stool softener.

--Had to do this week's blood draw a day early (y'day) while the roads were thawed.

That's it, status as it seems from here. Cheers and happy weekend.

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ProTime 1/11 reading
10.9 L

ProTime 1/19 reading
11.3 L

ProTime 1/25 reading

11.7

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To: Ivan C Doig

From: PATRICIA KATO, MD

Subject: RE: Starting therapy

Received: 1/2/07 6:56 PM

Dear Ivan,

I see that you pursued a second opinion, which I think was a good idea. It's nice to have two independent MDs giving you the same recommendations. Unfortunately, I do not have much personal experience with this problem or drug regimen. However, I will be here to support you and Carol in any way I can.

I will give you a call tomorrow. If you are not feeling up to talking on the phone, don't worry. I would also be happy to talk to Carol.

Best wishes always,
Pat Kato, MD

P.S. I loved the book. I was through it too soon, as I knew would be the case! My husband sends his best wishes as well.

----- Message -----

From: DOIG,IVAN C

Sent: 12/31/2006 3:07 PM

To: Office of PATRICIA KATO, MD

Subject: Starting therapy

Just FYI: on Jan. 1 I'm starting therapy (Thalidomide 200 mg/dexamethasone 40 mg/Coumadin 1 mg) as prescribed by Dr. Ginsberg, who intends to take my treatment all the way to stem cell. Am prepared and girded as much as I can be for this drug regimen, but any random advice from your experience with similar patients would be welcome; this is like going to grad school. Best from Carol and me.

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To: Ivan C Doig

From: STEVEN GINSBERG, MD

Subject: RE: vitamin B6

Received: 1/2/07 11:44 AM

I will get a B6 prescription to Northgate for you. Good luck and see you soon.

Steve

----- Message -----

From: DOIG,IVAN C

Sent: 12/31/2006 3:19 PM

To: Office of STEVEN GINSBERG, MD

Subject: vitamin B6

Hi; Dr. Becker's report came y'day and I flashed on her idea of vitamin B6 re: Thalidomide. OK if I add that to the pill list? If you prescribe, I could pick it up @ Northgate @ my 1st blood draw on Friday. As to the rest, I have 'em lined up ready to start on in the morn. Fingers are crossed, but I'll still get the pills down.

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To: Ivan C Doig
From: LYNN FLAHERTY, RN
Subject: RE: therapy side effects
Received: 1/4/07 2:32 PM

Hi Ivan

Thanks for the update. yes, I agree re start use of laxative and stool softener. Let us know about rash symptoms if they persist or get worse. Eucerin is fine to use for now, maybe some hydrocortisone over the counter cream if it starts to itch would be helpful.

LYNN FLAHERTY, RN

----- Message -----

From: DOIG,IVAN C
Sent: 1/4/2007 11:51 AM
To: Office of STEVEN GINSBERG, MD
Subject: therapy side effects

Dr G & Lynn--Rash appearing on my back. No itch (yet?)
Using Eucerin on it; adequate for now?
--Bowel movements lacking (plenteous gas, though). Got some stuff out y'day with fleet enema. Early as it is in therapy regimen, figured I'd resort to laxative/stool softener if nothing moves today; sound right?
Otherwise pretty much tolerating 1st phase Thal/dex OK.
A bit spacy 1st thing out of bed, but I get by with First Rule of Wingwalking: "Never leave hold of what you've got, until you've got hold of something else." Anyway, so far so good, I guess.

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Dec. 18 '06

Appointment with Dr. G's nurse Lynn Flaherty:

--went through the Thalidomide registration process, although when she called in to Celgene they waived my telephone survey this time.

--she had drawn up the Jan. calendar of taking pills. The daily routine:

breakfast: 10 dexamethasone, totaling 40 mg.

lunch (optional): Lynn said I can continue taking Glucosamine/Chondroitin, so I think I would shift those to here, if I can stand to take that many pills.

evening: Thalidomide, 1 capsule 200 mg.; Coumadin, 1 pill 1 mg.

Possible side effects:

Lynn and Seattle Cancer Care Alliance both provided (slightly different) handouts on all three main drugs, and each has a file folder of its own in my desk file drawer. Lynn cited as the most likely to effect me:

dexamethasone: She said the first day or two, I may feel really good, elevated; it makes a person wide awake, so it's best to take in daytime (hence breakfast). It can also make a person:

irritable; I had her prescribe Lorezapam as a calmativ.

hungry; C and I talked about what I can eat in this case that wouldn't pile on calories: applesauce, rice cakes w/ honey or low-cal cottage cheese; carrot sticks; apple.

"loopy"; this one I may just have to ride out unless Lorezapam helps; I think I'd see what effect it has on my writing, or listen to music or audio books on the MP3.

Other points:

--my white blood cell count will go down (it's called leukopenia) during therapy, to some kind of plateau. This will make me more susceptible to infections, so I should use Purrell instant sanitizer wipes a lot. She cited public instances such as after pumping gas, but stressed that I'll be my own worst source, hand-to-mouth contact; so I should be diligent as possible.

--I'm also to watch for **fever** of **100.5** or greater and let her know. Accordingly I bought an oral digital thermometer.

--my red blood cell count (the hematacrit reading) is also likely to go down, possibly as low as 33.

--she doubted that I will lose hair or beard, thinks I'll stay "bushy as ever."

--she said an occasional drink is okay, although not an "every night."

--sex without latex condoms is also okay according to her, as long as it's not with anyone who can have a kid. Told her I may not have the oomph during this anyway, she laughed and said you never know about the dexamethasone.

MORE

--I told her Dr. G (and for that matter Dr. Becker) said Pamidronate should also be used with this therapy regimen; she checked with him and he said to wait until next month.

--I asked her what to do if I have to squeal for help because of side effects, and she said e-mail her (or of course Dr. G) through the Gp H website.

--Lastly, when she was on the topic of stem cell transplant, Lynn surprised me by saying myeloma is "practically curable" with that procedure. That's more hopeful than Dr. Becker's statistics that stem-cell on the average adds a couple of years to a patient's prognosis, although she too stressed that a mini-transplant and other procedures can extend the life expectancy well beyond that. As I said to C about Lynn and Dr. G, these are optimistic folks and in the field they're in I guess they have to be.

In any case, as I left Lynn told me "we're going to care of this disease before it takes care of you."

Afterword: Carol said we have to make sure to have clear communication between the two of us about how I am feeling at any given time during this load of drugs, so I must work on that and she must prod me on it.

Duration of therapy did not come up in yesterday's session, as it surely will depend on Dr. G's assessment Jan. 29 assessment of how I'm doing. I am to reorder Thalidomide the week before I see him, so a second round of therapy is thereby anticipated. My assumption is that I'm in for three rounds of this, i.e. three months, and anything less is a beneficent turn of events.

We both divined from the dosages Dr. G. prescribed--the 200 mg. of Thalidomide without phasing it in--that he's being aggressive against my protein spike, and thinks I'm healthy enough to stand all this. During an earlier visit, he said my general health makes me fit for "optimal" treatment. Which means, sigh, these heavy doses that start on Jan. 1.

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Print Date 12/20/06

Dispensed at CENTRAL MED CTR SOUTH on 12/20/06 at 14:57 by 030848
Federal Tax ID: 91-0511770 Phone: 1.888.901.4636 NCPDP Number: 4906838

PATIENT: DOIG, IVAN (MEMBER# 00215848)
#####

Prescription Number	Date Of Service	NDC	Days Qty Supply	Price	Patient Charge	Reason
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3546-6039-401	12/20/06		50 20	10.90	10.00	Cost Share
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LORAZEPAM 1 MG TABS (NDC 0228-2059-10)

Prescriber: GINSBERG, S S if needed

3546-6045-701	12/20/06		30 30	13.00	10.00	Cost Share
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WARFARIN 1 MG TABS (NDC 0555-0831-02)

Prescriber: GINSBERG, S S 1 pill nightly

3546-6054-801	12/20/06		120 28	27.10	10.00	Cost Share
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DEXAMETHASONE 4 MG TABS (NDC 0054-4184-25)

Prescriber: GINSBERG, S S 10 pills (40 mg) at breakfast, 4 days on, 4 days off

3546-6116-501	12/20/06		28 28	3,506.00	30.00	Cost Share
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THALIDOMIDE 200 MG CAPS

Prescriber: GINSBERG, S S 1 capsule nightly

3546-6235-101	12/20/06		100 30	4.80	4.80	Not Covered
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DOCUSATE SODIUM 250 MG CAPS (NDC 54629-601-01)

Prescriber: OVER THE COUNTER 1 pill mid-morning

Prescriber: OVER THE COUNTER 1 pill mid-morning

3546-6235-201	12/20/06		100 30	4.90	4.90	Not Covered
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SENNA CONC TABS (NDC 0182-1093-01)

Prescriber: OVER THE COUNTER 1 pill mid-morning

Prescriber: OVER THE COUNTER 1 pill mid-morning

added: PYRIDOXINE (vitamin B6) 50 mg 2 pills at lunch

Account 046026010 Charges: 70.55/Pre-payments: 70.55/Due: 0.00

taken as needed during
dexamethasone 'pulses'

TEMAZAPAM sleeping
pills

2 pills 2 hrs before
bedtime

Charges 70.55/Pre-payments: 70.55*Due: 0.00*

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PATIENT: DOIG, IVAN (MEMBER# 00215848)
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Prescription Number	Date Of Service	NDC	Days	Qty Supply	Price	Patient Charge	Reason
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3546-6039-401	12/20/06	50	20	10.90	10.00	Cost Share
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LORAZEPAM 1 MG TABS (NDC 0228-2059-10)

Prescriber: GINSBERG, S S if needed

3546-6045-701	12/20/06	30	30	13.00	10.00	Cost Share
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WARFARIN 1 MG TABS (NDC 0555-0831-02)

Prescriber: GINSBERG, S S 1 pill nightly

3546-6054-801	12/20/06	120	28	27.10	10.00	Cost Share
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DEXAMETHASONE 4 MG TABS (NDC 0054-4184-25)

Prescriber: GINSBERG, S S 10 pills (40 mg) at breakfast, 4 days on, 4 days off

3546-6116-501	12/20/06	28	28	3,506.00	30.00	Cost Share
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THALIDOMIDE 200 MG CAPS

Prescriber: GINSBERG, S S 1 capsule nightly

3546-6235-101	12/20/06	100	30	4.80	4.80	Not Covered
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DOCUSATE SODIUM 250 MG CAPS (NDC 54629-601-01)

Prescriber: OVER THE COUNTER 1 pill mid-morning

3546-6235-201	12/20/06	100	30	4.90	4.90	Not Covered
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SENNA CONC TABS (NDC 0182-1093-01)

Prescriber: OVER THE COUNTER 1 pill mid-morning

added: PYRIDOXINE (vitamin B6) 50 mg 2 pills at lunch

Account 046026010 Charges: 70.55/Pre-payments: 70.55/Due: 0.00

Total Patient Charges 70.55/Pre-payments: 70.55*Due: 0.00*

The above item(s) have been charged to your bank card. This amount will appear on your statement as "Group Health Pharmacy."

This document is your receipt. Thank you for using your Group Health Pharmacy.

This document contains confidential information about your health and care. This is provided directly to you for your personal, private use only.

Dec. 18 '06

Call Dr. Becker's nurse this morning:

Good morning, this is Ivan Doig, and my Cancer Care Alliance medical number is U2 56 39 19. I'm a Group Health patient of Dr. Ginsberg, who referred me to Dr. Becker for a second opinion about my case of indolent myeloma, on Dec. 6, and I'm following up on two matters from my session with Dr. Becker:

--has she seen Group Health's chromosome analysis (FISH test) in my case yet, and does it alter her original suggestion of therapy consisting of Thalidomide and dexamethasone?

--is her written report ready, and if so, could it be faxed to me?

Dr. Ginsberg by e-mail and/or phone:

--does the chromosome analysis (FISH test) still indicate to him the therapy consisting of Thalidomide and dexamethasone?

--I'd like to have all the preliminaries done and the pills on hand to begin the therapy on Jan. 1. How do we proceed to that?

phone reply from his nurse Lynn Flaherty @ 2:15:

--she does not see FISH test results on my electronic chart, but will ask Dr. G about it. Because she is off next week, and she says the Thalidex therapy can be strengthened if the FISH test results indicate it should be, we agreed that I should come in this week and do the paperwork etc. to get started on Jan. 1. **Appointment: 1 pm, Wed. 20th.**

--Thalidomide paperwork and telephone survey must be done for Celgene; it will furnish only 28 days of Thalidomide at a time, so I must notify Lynn a week ahead of when my pills will run out. Central Pharmacy is the only place I can pick them up.

--She'll also have the dexamethasone 4-day 'pulse' schedule written out for me, and they prescribe 1 mg of Coumadin along with the other drugs.

--She commented that one thing about myeloma is that it is "pretty treatable."

I didn't think to ask, but will figure I need to schedule a January appointment with Dr. G when I go in on Wed. Also must ask her whether I need to put Northgate blood tests (and 24-hour urine test?) on my calendar.

- Pamidronate?
- Glucosamine / Chondroitin?
- take tape recorder
- take my calendar?
- anxiety drug? Lorazepam
- stool softener?
- when to expect hair loss?
- off alcohol, or not?

Dec. 18 '06

Call Dr. Becker's nurse this morning:

MTW/

D-C-1-6

Janice called back,
late afternoon

Good morning, this is Ivan Doig, and my Cancer Care Alliance medical number is U2 56 39 19. I'm a Group Health patient of Dr. Ginsberg, who referred me to Dr. Becker for a second opinion about my case of indolent myeloma, on Dec. 6, and I'm following up on two matters from my session with Dr. Becker:

print of cell

--has she seen Group Health's chromosome analysis (FISH test) in my case yet, and does it alter her original suggestion of therapy consisting of Thalidomide and dexamethasone?

on her session w/ me

--is her written report ready, and if so, could it be faxed to me? *She'll check on report*

neg for deletion 13 - no change
to Thalidomide
recommendation

Dr. Ginsberg by e-mail and/or phone:

M-Th/ W/ 20th
1 pm

--does the chromosome analysis (FISH test) still indicate to him the therapy consisting of Thalidomide and dexamethasone?

--I'd like to have all the preliminaries done and the pills on hand to begin the therapy on Jan. 1. How do we proceed to that?

Calgene: p/work / tel survey m'ly / alert

- prescribe 1 mo/a + time (2-3 days) / ~~3~~ wk's notice to Lynn

- Central Ph'cy to pick up /

- Dot 4 day pulses /

pretty treatable

Capecitabine

initiate /
Lynn /
#shortly

Dec. 20 '06

From Steven Ginsberg
Sent Dec 19, 2006 11:55 AM
To Lynn Flaherty

lorazepam
warfarin

plavix

senna - laxative
Doss - stool
softener

**Clinical Order - No
Procedures (No
LOS)**

Ivan C Doig (MR# 00215848)

Visit Information	Date	Time	Department	Provider
	12/19/2006	11:40 AM	CSC ONCOLOGY	STEVEN GINSBERG, MD

Visit Summary

Diagnoses Visit Diagnosis
MYELOMA [203.00S]

Allergies as of (No Known Allergies)
12/19/2006 **Date Reviewed:** 05/22/2006

Vitals

Default Flowsheet Data (all recorded)

****No Flowsheet Template found****

Progress Notes

Medications

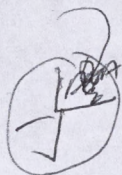
Prescriptions Ordered This Encounter	Prescriptions	Disp	Refills	Start	End
	THALIDOMIDE (THALOMID) 200 MG ORAL CAP Sig: 1 pill daily Route: ORAL Non-formulary Exception Code: B. Patient meets criteria for use	28	2/2	12/19/2006	
	DEXAMETHASONE 4 MG ORAL TAB Sig: 10 pills daily days 1-4, 9-12, 17-20; repeat every 28 days Route: ORAL	120	2/2	12/19/2006	

200mg pills

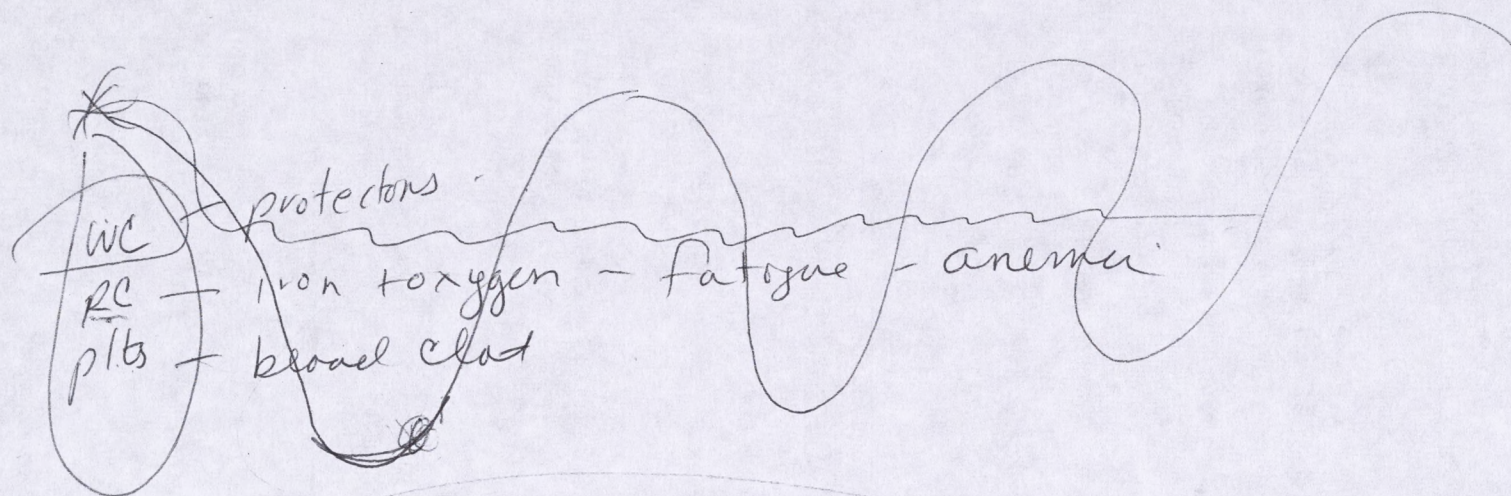
Outpatient Active Meds	Prescriptions	Dosage
	THALIDOMIDE (THALOMID) 200 MG ORAL CAP	1 pill daily
	DEXAMETHASONE 4 MG ORAL TAB	10 pills daily days 1-4, 9-12, 17-20; repeat every 28 days

Orders

Visit Diagnoses and Associated Orders **MYELOMA [203.00S] - Primary Dx**
THALIDOMIDE (THALOMID) 200 MG ORAL CAP [52680]
DEXAMETHASONE 4 MG ORAL TAB [2221]



7-10 days



fever 100.5 or greater

38-40



33

— procrit ↑ RBC

oral digital thermometer

parrell instant sanitizer

Dex - (at day 2, feel good; wide awake, take in daylight
- irritable; hungry; can be loopy

1 cycle

- probably not here long
- mild w. all decline

Warfarin -
evening

Dec. 8 '06

Questions for Dr. Ginsberg

1. Carol and I thought that was a highly useful session with Dr. Becker; we can see why you prize her as a colleague.

My understanding was she wanted a closer look at a chromosome analysis for abnormalities, which could suggest a more aggressive start of therapy? Has that been resolved?

Dr. G: he'll order up the FISH study from the bone marrow test I took.

2. She told us (we think, from our reams of notes) that the induction therapy she would standardly use steps up the dosage as it goes along--beginning with 50 mg. of Thalidomide for 2 weeks, then 100 mg. for 2 weeks, then 200 for 2 weeks--does that line up with your thinking?

Dr. G: yes.

Which part of that is likely to be tougher for the patient--the first doses or the last level?

Dr. G: He's found 100 mg is "easily tolerated," beyond 200 can be tough.

And the dexamethasone is given in "pulses" of 4 days on, 4 days off?

Dr. G: Yes, 40 mg. doses

And Coumadin along with it all?

Dr. G: Yes, low dose--1 mg/day--unless Dr. Becker thinks I'd need more.

3. How do we proceed?

Dr. G: He e-mailed Dr. Becker earlier today and is waiting to hear back from her, and also waiting for the fax of her report. If I don't hear from him by next Friday, I should call.

He asked what schedule I'd prefer--wait until after holidays, in case there are side effects?--and I said I'd just as soon get started.

(Is it OK to start this in the holiday season, on the chance any problems occur? Medical staffs surely have some kind of time off, and schedule juggling, don't they?)

Dr. G: He says Gp H stays at full service, except on Christmas and New Year's.

4. What's the best way to reach you during this if something comes up serious enough that I feel I really have to?

Dr. G: His nurse Lynn's phone number 326-2645. But the best way to reach him, he stressed, is e-mail; he says he looks at it "ten times an hour."

Dec. 5 '06

In today's session with Dr. Ginsberg, C and I took in the list of questions on the next page, which produced the main news that in his opinion I should have induction therapy of Thalidomide-dexamethasone combination for 1-3 months and then a stem cells transplant.

--He said I am in a "gray area," the myeloma either smoldering or indolent, but the rise in the protein counts (the latest test, 24-hr urine, showing a continuing spike) bothers him.

--He made the point that right now I am in good health and thus can withstand "optimal" therapy (the chemo regimen during the transplant process, I think he meant). He does not want to wait 6-12 months to see how the protein readings go; as he said, what if I have an unfavorable turn of health (a heart attack was the example he gave) in the meantime.

The stem cell transplant process as he outlined it:

--the one to three months of induction therapy mentioned above; the combination of drugs is regarded as having a 75% success rate, as opposed to Thaliidomide alone 35-40%, dexamethasone alone 40-60%.

--the blood collection is done at the Hutchinson, 3-4 hours on a machine, 1-4 days. Leading up to that are injections of Neupogen, either done here at home or Gp H.

--when re-infusion is performed, there's a two-day 2-hr chemotherapy (I think it's Melphalan intravenously) that goes with it that is potentially nauseating. 60% of patients need hospitalization for this because the chemo causes inflammation of the gastro-intestinal tract; difficult to swallow, and there's diarrhea.

--it takes 2 weeks to blood count recovery.

--I should feel "pretty well" after 1 month.

--I should feel "normal" after 2-3 months.

Other points:

--he would include Pamidronate in the course of treatment (monthly infusion for a year) although as C points out, he goes back and forth on how worthwhile it is. The only definite research is that it slightly decreases chance of spinal compression fractures in myeloma patients.

--he can give me medications for sleeplessness and anxiety (Lorezapam) if I have those side effects from the induction therapy.

--my creatinine level, which measures metabolized kidney waste, is "normal," eliminating one complication to stem cell transplant process.

wt 158 w/ sport jacket bed pressure 124/70

Dec. 5 '06

Questions for Dr. Ginsberg:

1. Where do you think I am on the list of phases--smoldering, indolent, Stage 1 and so forth?

(The referral sheet to the Cancer Care Alliance refers to "indolent.")

--And the classifications of "inactive" and "active" that the Myeloma Research Foundation website has--which am I by now? Does that depend on whether treatment has started or not?

(The website defines "inactive" as no evidence of myeloma-related organ or tissue impairment.)

active

2. Is Pamidronate still an option?

yes in certain cases
active - 12mo

(If so, I'd like to proceed with it.)

--If we're beyond simply Pamidronate, which treatment seems best to you?

(If the second opinion and suggested treatment coincides with your evaluation, I'd like to proceed as soon as possible.)

--As a guide to my own thinking on treatment decisions, do I qualify as a potential stem cell transplant candidate?

3. Again, if the second opinion supports yours, what is the likely trajectory of my case?

Lastly, what points do you want me to be sure to cover with Dr. Becker tomorrow?

(FYI: the one specific question Dr. Becker's patient coordinator asked after receiving the fax of my medical record was whether there was a more recent bone marrow test than last April's.)

collection @ Hunter
3-4 hrs / machine

1-3/4 days

25% comb
40-60 days

35-40 Thal

1-3 mo / stem cell

old collection

inject Neupogen - 2-CE5

2-day 2-hr chemo
(nauseating)

SF

Dec. 5 '06 reminders to myself:

--how soon will you have Dr. Becker's report and we'll be deciding what our course of action is?

can call before

--next office visit, or by phone?

Thalidomide:

--is it feasible to start with Thalidomide and add Dexamethasone if necessary?

--during treatment, are there medications I can take to counteract depression and/or sleeplessness?

leukemia pamphlet given me at time of MGUS diagnosis: still the fullest glossary on my case?

- earliest appt w/ Dr. B was tomorrow
- goes to help C & me w/ terminology
- Revlimid: A do- like possibility of a placebo

→ was to bid if necessary (may need transfusion)
 60% hospitalized (2-4 days)
 Melphalan / 2-day i-v / ^{gastro-intestinal} inflammation
 ↓
 - feel pretty well after 1 mo
 2-3 mo "normal"
 ↓
 swallow & diarrhea

Creatinine: metabolized kidney waste

Yale

Fri/phone visit 3-3:30

Lorazepam/anxiety

Ginsberg visit, Dec. 5, 2006

Dr. G is proceeding on the assumption that the numbers are going to get worse, and ~~and~~ that you're going to need to go under treatment, so the sooner the better.

IS THERE ANY REALISTIC LIKELIHOOD that the numbers will stall out and leave you in the gray area? (In what percentage of cases may that be true, if ~~about~~ any?)

He goes back and forth about Pamidronate. WHAT IS Dr. Becker's view of its usefulness?

IF DR. BECKER believes treatment now is best, would she use the same thal-dex-stem cell therapy as G.?

WHAT IS the success rate of that therapy? What is the next step if it doesn't work for you? What is the mortality rate? What is meant by "success" since there's no current cure? Assuming remission, for how long is that likely to last?

DOES SHE have a similar sequence of treatment for thal-dex-stem cells as G?

IF YOU decide to wait on treatment, does that put you at greater risk in the long run? Put another way, are the risks of waiting greater than the risks inherent in the therapy?

What about starting w/ thal. alone. Why not try it, and add-on if results are not satisfactory?

I am a writer of fiction, an activity that takes all of the mental acuity I've got. Could this (the 3-part) treatment or any part of it permanently alter my intellectual ability or my ability to concentrate?

(Ivan fyi - this is particularly aimed at chemo)

Group Health Cooperative
Pharmacy Dispensing List

Print Date 12/20/06

Dispensed at CENTRAL MED CTR SOUTH on 12/20/06 at 14:57 by 030848
Federal Tax ID: 91-0511770 Phone: 1.888.901.4636 NCPDP Number: 4906838

PATIENT: DOIG, IVAN (MEMBER# 00215848)
#####

Prescription Number	Date Of Service	NDC Days Qty Supply	Price	Patient Charge	Charge Reason
------------------------	--------------------	------------------------	-------	-------------------	---------------

3546-6039-401	12/20/06	50 20	10.90	10.00	Cost Share
LORAZEPAM 1 MG TABS (NDC 0228-2059-10)					
Prescriber: GINSBERG, S S					

3546-6045-701	12/20/06	30 30	13.00	10.00	Cost Share
WARFARIN 1 MG TABS (NDC 0555-0831-02)					
Prescriber: GINSBERG, S S					

3546-6054-801	12/20/06	120 28	27.10	10.00	Cost Share
DEXAMETHASONE 4 MG TABS (NDC 0054-4184-25)					
Prescriber: GINSBERG, S S					

3546-6116-501	12/20/06	28 28	3,506.00	30.00	Cost Share
THALIDOMIDE 200 MG CAPS					
Prescriber: GINSBERG, S S					

3546-6235-101	12/20/06	100 30	4.80	4.80	Not Covered
				.42	Sales Tax
DOCUSATE SODIUM 250 MG CAPS (NDC 54629-601-01)					
Prescriber: OVER THE COUNTER					

3546-6235-201	12/20/06	100 30	4.90	4.90	Not Covered
				.43	Sales Tax
SENNA CONC TABS (NDC 0182-1093-01)					
Prescriber: OVER THE COUNTER					

Account 046026010 Charges: 70.55/Pre-payments: 70.55/Due: 0.00

PRESCRIPTIONS

Nov. 9 '06:

In the aftermath of Dr. G's "scared" reading of my spiking blood-protein level yesterday, I:

--left a phone message asking him for a referral to Dr. Pam Becker at Seattle Cancer Care Alliance and to let me know when it's been made, so I can proceed with an appointment to get the second opinion he strongly suggested.

--reorganized the accumulated material from the nearly six years of seeing him into individual folders, such as test results, clippings on cancer research, etc., after reviewing it all (and C reviewed the most pertinent files).

--looked over the paperwork on a double-blind placebo regimen which would give me a 50-50 chance of receiving Celgene's expensive new cancer drug, Revlimid. My conclusion there was that I don't want the factor of a placebo in my treatment, I want health care professionals working with their best definite knowledge.

That leaves me with this situation: trying to divine, from a combination of the second opinion and my Dec. 5 session with Dr. G (when he will have results of protein reading in a 24-hr urine sample I'm to do, to add to the latest blood tests), at what point I should start aggressive treatment. Talking this over with C, we came to these points and considerations:

--has this gone past the Pamidronate bone-strengthening option?

--of the three possible treatments Dr. G cited to me (Thalidomide/dexamethasone evidently the primary one to him), am I okay to go for the least side effects or must I choose something maximal and back off if I can't tolerate it? C makes the point that I should ask him about the third treatment he cited to me, prednisone and I think melphalan (that's the combo listed in the Revlimid paperwork's "alternatives" as among "standard combination chemotherapy regimens"); as she's found, prednisone is no picnic but it may not have side effects as dire as those possible with dexamethasone.

--there are a number of drugs in the pipeline, and a year ago--before the blood protein spiking--Dr. G was counseling me to wait on any treatment because drug advances have steadily come along, lengthening survival time of myeloma patients by a few years. Is any waiting of that sort still in the picture?

2/14/01 Condition: "slightly anemic" (red cell count? 36? should be 38-48?)

Kato thinks s'thing is wrong:

- "s'thing in bone marrow" / not producing cells
does smc = a cancer?
- "cd be inflammatory" (I don't feel any signs)
- rheum'd arthritis (" " " ")

conclusion: be prepared to grapple pretty hard as Ginsburg's diagnostic process narrows things down.

- press him to put things in layman's English

after seeing Ginsburg:

further tests?

- baseline
- relieve my mind?
- instinct: "I'm not gel w/ uncertainty."
- if test is positive, I'll at least know situation

wait for pure results?

2 of 7 symptoms no big deal?

tests wld' rule out for good (25% MBUS get mult myel)

Dr. G. thinks it's MBUS, not mult myel

tests will inevitably take a while to schedule: 2-4 wks?

- 6/1/01 150 mg protein in urine; 1 gram is level of concern
- Oct 16/01 Thalidomide then used in "refractory" cases
- Gp X doing stem cell work
- 2/27/02 190 chance/yr
- 2/24/04 48 centigrams protein in urine / for patient w/ 5 grams
- 2/24/06 concern abt lymphocytes
- 4/26/06 30% plasma cells in bone marrow test; 10% level of concern
- total X-ray; once bone lesions are found, ave. of 1 yr to myeloma
- 4/25/06 - X-ray shows no lesions
- ave. survival when treatment starts is 5-7 yrs.
- Aug 16/06 G favored holding off on myeloma treatments; suggests 1 yr Pandina
- Nov. 8/06 protein spike goes up or 1623 mg
- Nov. 16/06 24-hr urine test: 4960 mg; spike 33% of urine protein

Myeloma website:

Treatment options: most common, melphalan & prednisone

- older patients, dexamethasone & Thalidomide

stem cell transplant: melphalan improves

- thalidomide & dex most freq'ly used in transplant candidates
(sometimes VAD or DVd)

3-4 cycles of therapy, then stem cells collection for transplant

Chemotherapy

- induction therapy, ahead of transplant

radiation: 1/2 of body's bone marrow in pelvic bones

stem cell transplantation: 4700 transplants in '03 for myeloma

- autologous: from same individual allogeneic: someone else

long-term side effects

sample p 17 stem c gnr

" p 19 side effects (beard: shave it off early?)

(tape recorder? laptop?)

106

8 Nov. 74--My protein level has continued to spike--2.7 g., up from 2.1 in July and 1.4 in Feb.--indicating to Dr. G. that "the myeloma is advancing." My other vital test results, creatinine, calcium, hematocrit, remain within the range they've been since we started this nearly 6 years ago. He finds this puzzling enough, and not clearcut enough to dictate a given course of treatment, that he recommends a 2nd opinion @ the Seattle Cancer Care Alliance, and I have just left a phone message asking him for a referral to Dr. Pam Becker, who he mentioned is involved in stem-cell research. His other recommended dr. there is Bill Bensinger, an older myeloma specialist; I am choosing Becker (who is of Ginsberg's generation) because she may be closer to cutting-edge research.

I went in, today, prepared to okay the start of pamidronate infusions for the next year, on a bone-strengthening basis, but we weren't very far into the session and discussion of that than Dr. G, I think more and more spooked by the sharply spiking protein level (which means the dreaded IGA monoclonal protein most conducive to myeloma), brought up other treatments:

--the 1st he mentioned, I think the most standard is thalidomide and the steroid dexamethasone (pills in both cases), administered in a complicated 4 days on, 4 days off, mixed with other on & off, totaling 35 days. I asked if the timespan of taking these was open-ended, and he cited three 35-day doses to see if the treatment would, preferably, "get rid of" the protein spike or at least plateau it. He says some people tolerate dexamethasone okay, but possible side effects are numbness of fingertips and toes, anxiety, sleeplessness.

OVER

***The next possibility he mentioned he seemed to have some enthusiasm for, is a blind test (i.e., placebo) in which I'd have a 50-50% chance of getting the thalidomide-dex *** treatment or a new drug (I see it's not named in the handout but I think he said it was ~~Leverol~~) and dexamethasone. I'm to look over the handout/consent form and let him know. Revlimid

--Lastly he mentioned a combination of ~~Revlimid and Lentin~~ a drug whose name I didn't catch* and prednisone. *likely melphalan

He also ordered up another 24-hr urine sample from me, to measure the protein in that, and I'm to see him again on Dec. 5. Pending the 2nd opinion, I'll need to decide on a course of treatment then.

***IMPORTANT: I either misunderstood Dr. G or he misspoke: the 50-50% chance is not for thalidomide instead of Revlimid, but purely a placebo. In short, if you don't luck out on the Revlimid, it's a dexamethasone treatment--which can have its own effectiveness but carries most of the side effects.

Bld pressure: 120/60; wt 161 w/ sportcoat on

16 Aug. '06:

Bld test results were not dire--creatinine, calcium, hematocrit, lymphocytes about what they were last time--~~the~~ but the protein level keeps going up. So, it is still smoldering myeloma rather than flaring, but the advancing protein level--as I understand it, this indicates the monoclonal gamma globulins--is worrisome. Two pertinent things from Dr. G this time, in light of this reading:

--He favors holding off on any myeloma treatment now because treatments--i.e., drugs--have steadily improved; better than they were 5 years ago, and indications are they'll be better yet 5 years from now, as he put it.

--He would like to put me on Pamidronate for a year, probably starting in Nov. when he next sees me and has the next set of bld test readings. It might bring the protein level down, although he stressed that we don't know that, and in ^{any} case, it and calcium and vitamin D along with it would mineralize the bones--one thing myeloma does is demineralize them. This to him is a separate category from the hold-off-on-treatment notion--it's purely to strengthen bones--and it makes sense to me. He would hold the Pamidronate use to 1 year, as the research on osteonecrosis it can cause indicates ~~xxxx~~ usage of more than a year creates that risk. Once a month, 45 min. of intravenous. Will make him go over possible side effects more thoroughly, but all else being equal, I think I'll do it.

25 April '06:

As C said when I gave her the news from Dr. G's phone call, "You finally got a break." Indeed, the result of the total-body X-ray scan was "normal," i.e. no lesions indicating actual myeloma. Dr. G made these points:

--the scan and the beta 2 blood test he regards as "the most important" of the several indicators he's tracking on me, and they're both "normal," i.e. the beta 2 ~~ix~~ of 1.6 is quite within the range of 1.1-2.4, (the higher the number, the worse). My other numbers are "encouraging."

--this puts me at "the best end of the spectrum". He pointed out ~~myx~~ smoldering myeloma can go on for years and years, and even when treatment does start, the survival average now is 5-7 years--ten years ago, he said, it was less than 3 years. He also said, the first time I've heard him utter anything of this sort, that he has hope there may be treatment that'll be a cure by the time anything dire starts with me. I'm not persuaded by that, as there's also the troublesome average that people with smoldering myeloma may require treatment within 3-5 years, but I'm a bit heartened.

He wants to see me 3 months from now, early August, for the next blood tests.

OVER

I asked him about taking Pamidronate, starting in August, and without pushing it he thinks it'd be OK if I want to. This was before C told me about a WSJ article today on bone problems from such drugs, so I may change my mind. But if I do stick to my thinking that bone-strengthening is a worthwhile idea even at my low stage of this, I would have to do the intravenous at Cap Hill; schedule it about a week ahead; and would not have to do it at exact 1-month intervals--4-5 wks is okay, and can skip a month if need be. I asked him if it's easy to get off the stuff if there are side effects--i.e., does the body get hooked on it--and he said it can be quit with no problem.

20 April '06:

Hard news, on the result of the bone marrow test: 30% plasma cells, and 10% begins to be the area of concern. So, Dr. G at once ordered up 2 more blood tests (for immunoglobulins) and I went down to radiology and had a total body set of X-rays, so he can look for any bone lesions. If there are bone lesions--the errant cells starting to make "Swiss cheese" of the insides of bones--then on average ~~examined~~ it's a year until onset of myeloma.

For now, as C and I heard it (I had her sit in on this important verdict session), he considers my case as tending into the "smoldering myeloma" category. He stressed again that people can have this for years and years with no significant change. He pointed out I am otherwise healthy and feeling fine, showing no signs of real myeloma. The point, C and I agree, is to go on with life as nearly normal as possible, until there ever is a change.

Dr. G did give me the option of monthly intravenous Pamidronate, a bonebuilding drug that doesn't have proven results yet. Depending on what I hear ~~if~~ from him in his phone report on the X-rays on the 25th, my inclination is to hold off until August, after the book tour, before starting that; a possible side effect is fatigue.

wt: 161 w/ cord jacket on Bld pressure 130.75

Over

The monoclonal protein showing up in the marrow test is IgA lambda; the Mayo Clinic study shows that as a heightened chance of developing myeloma. The reading is now 1.4, and the initial reading some years ago was .5.

Carol's notes
from Ivan's visit to Dr. Ginsberg
April 20, 2006

While Ivan was busy processing the numbers, I was looking for impressions and general statements.

Dr. Ginsberg described the changes in the blood test results as "subtle." Ivan's readings are right on the edge between MGUS and myeloma, and he would classify the current results as ticking into the "smoldering" category.

At one point he was explaining the readings and said, "If, after another five years..." the counts do this or that. I didn't catch the full context, but I did read process into it. At another point he said "Follow AND track" in terms of test results.

Ginsberg isn't eager to begin treatments, other than possibly pomidrimate (?), which would be administered intravenously once a month. It is aimed at remineralizing bone. He said, however, that the jury is out as to its effectiveness.

Ivan feels well, and Ginsberg expects him to go on about life, as usual. He didn't wince when Ivan showed the book tour schedule. He did say that perhaps he could show up at Elliot Bay on June 1.

13 April '06:

This afternoon at about 4:40, running nearly an hour late, Dr. Ginsberg did the hipbone marrow test. It took probably 10 minutes of lying on my stomach, while he swabbed the area above my right buttock w/ iodine solution, numbed it with a couple of shots, then forced in the needle to extract (as he showed me) a small gristly-looking sample of marrow and bone specules in what looked like a test tube of blood.

Getting ready, he said there wasn't much to the test. I said the procedure wasn't what I was worried about. He asked, What, then? What he might find, I said. He replied that he couldn't help me there, but whatever we did find will have been there "a long time." Possibly I should be heartened by that, since my test results have been acceptable up until this recent stint, of the past couple of months, and I don't discern any symptoms in myself such as fatigue or unusual aches. But my hunch is, given the high protein reading in the urine test and Dr. G's decision to do the hip test after half a dozen years of both of us skirting away from it, he expects to find some level of myeloma. He wants to see me, about the test results--and who knows what beyond that--in a week, April 20, 10:20 a.m.

wt: 158 w/ sptcoat on Bld pressure (after all the time spent in waiting rm) 121/70.

Feb. 24 '06 exam w/ Dr. Ginsberg

One unwanted reading from the blood tests, this time: lymphocytes, up twice as high as the reading a year ago. Dr. G says he does not know what to make of it, as the other measures of concern--creatinine, white cell count, blood protein--have not moved significantly. This has to be paid attention to, as excessive lymphocytes are an indicator of lymphoma as well as multiple myeloma--although an illness, possibly the colds I've had this winter (and for that matter still have a low-grade sinus nag), might elevate the count. Accordingly, he:

- examined my lymph nodes, tapped my spleen and so on; no physical signs of lymphoma.
- wants me to repeat the blood tests in 4 weeks, and do a 24-hour urine sample (to check the protein level there) as well.
- had me set up a phone consultation with him on April 6, after he's had a chance to review this second set of tests.

If the results bother him, he then wants to do the hip bone marrow test. Alternative would be the total body X-ray he had done 5 years ago, but as he says, that is a lot of radiation, and I have to agree with him that if the test results are really iffy, we'd better see how the bone marrow tests out. He emphasized to me that even if the hipbone test shows the presence of myeloma, it could well be low-grade enough (he didn't use the word, but the Cancer Society booklet's term is "smoldering") that our regimen on this won't change--the condition would just have to have a different name on it. That would be a psychological bridge I don't want to cross, but the possibility has always been there. Bld pressure 140/66 (traffic & I was late) wt 160 w/ cord jacket on

Feb. 25 '05 exam w/ Dr. Ginsberg

Reprieve! Test results were better--hematocrit up to 38 (from 36 six mos. ago), creatinine steady, white cells a little better, protein in blood not substantially worse--and after 4 years of looking at these, Dr. G. concludes I simply have borderline readings; regarding the critical hematocrit, I've had borderline numbers back to 10 years ago (39) and close to that 15 years ago (43). All in all, ~~the~~ thought we can space these exams out to a year, if I'm comfortable with that, and I said ~~he~~ ^I was.

Most vitally, he said it seems to him I may never develop myeloma out of this, or to look at it another way, if he examined me for 20 years there'd be about a 20% chance of my getting it.

He suggested I should get on-line w/ Grp H so I can see my files, and I agreed, stopping down @ the biz office and choosing the password 1188ACES.

Bld pressure: 130/60* wt 155 (w/ sportcoat off & glasses & wallet in it; 153 stripped
*news a few hrs before of Ben Baldwin's death on home scale
likely affected this

Aug. 13 '04 exam w/ Dr. Ginsberg--

Test results were in same range as past ones, but perhaps no more favorable than that. The hematocrit reading was 36, the anemic indicator which started this diagnosis, and the white blood cell count was down. Dr. G brought up on the computer the bar graphs of readings across the past $3\frac{1}{2}$ years, and said if he had only the past 3 or 4 readings it would look like a downward trend which would concern him; but over all, it's an up and down trend, not conclusive. The low white cells count --rather, the downward trend--would be a troublesome indicator only if myeloma was advanced, and no other indicators show that. So, he suggested we consider this status quo; asked me if I was comfortable w/ that, I said I was comfortable w/ him (i.e., his approach to this).

NOTE: he said the one more definitive test is the needle into the hip to test bone marrow. If he did that and it showed presence of myeloma, it would only change the diagnosis from MGUS to smoldering myeloma and the treatment would remain the same-- i.e., I wouldn't be in dire straits until other indicators worsened. I grasped from this that Dr. G is giving me a kind of furlough from a possibly troubling finding; that the needle test when and if it comes may be the turn of the corner to living w/ myeloma.

So: not as good a report as I'd want, but not dreadful yet.

Bld pressure: 116/60; wt 154 (in short sleeves & khakis)

Feb. 24 '04 exam w/ Dr. Ginsberg--

Blood test results again were unchanged; steady nonsignificant readings for 3 years now. That is, he says the readings show me as borderline anemic (in MGUS sense of anemic), and the 24-hr urine test showed some protein presence (48 centigrams if I understood the measure properly; he said he's working w/ a patient who has 5 grams) but nothing alarming.

--I'm to see him again in August.

Bld pressure: 100/60; wt 155 (in brown tweed sportcoat, w/ glasses in pocket, & wallet)

Sept. 2 '03 exam w/ Dr. Ginsberg--

Blood test results were stable enough; the hematocrit reading was 37, not down significantly--in fact, it was at that some years ago, before the "anemic" 36.

Dr. G wants to keep on w/ exams every 6 months; next time, along w/ blood tests I'm to do a 24-hr urine specimen again.

Bld pressure: 120/70; wt 154 (in summer clothes, w/ recent diet result)

Feb. 26 '03 exam w/ Dr. Ginsberg--

Blood test results are again untroubling; in fact, the hematocrit reading which triggered the MGUS diagnosis with an "anemic" 36 a couple of years ago now is a normal 40.

I asked Dr. G about advisability of a colonoscopy and the controversial PSA test; he favors doing both. I asked him to go ahead and put me in for a colonoscopy, and I'm to hear from the gastro-enterology dept. about that. The PSA test, which he favors on basis of a large-scale Canadian study that showed that men ~~who~~ over 60 who had the test lived longer than those who didn't, I still want to think over and perhaps link to my next physical with Dr. Kato. (If I decide I want one with my next blood tests, I can simply checkmark it near bottom of right-hand column on the green apptmt sheet he gave me) Dr. G did say that a person has to think ahead about what he wants to do if the PSA reading is high, say 10 or so; and according to my reading that of course has always been the rap against the test.

Bld pressure: 114/80; wt 166

Aug. 29 '02 exam w/ Dr. Ginsberg--

Blood test results blessedly unchanged; figures have stayed quite steady across all the exams thus far. See him again in Feb. '03.

Bld pressure: 110/60; wt 161

Feb. 27 '02 exam w/ Dr. Ginsberg--

Blood test results unchanged one more time, good news; we now go to 6-month exam interval, instead of every 4.

Dr. G gave me a brand-new NE Journal of Medicine article which he says indicates that MGUS patients have a 1% chance per year of it becoming myeloma; i.e., it sounds like a somewhat better statistic than the "25% get it" standard he told me about originally.

Bld pressure: 120/70; wt 165, both exactly as last time.

Oct. 16 '01 exam w/ Dr. Ginsberg--

Blood test results again unchanged--"fine," said Dr. G. Most importantly, the protein spike is no higher than in the 2 previous tests.

Wants to see me in Feb. to complete this every-4-months checkup sequence, then if ~~the~~ results still are stable, a 6-mo. exam; and if that is stable, to a once-a-year regimen.

Plainly Dr. G regarded this test's results as strong good news; and it's probable he feels more attuned to me, in a way perhaps has more of a stake in my case, now that he's reading my work, specifically Bucking the Sun.

Asked him abt research developments, and he confirmed there is quite a lot going on: thalidomide, though he said it's mostly used in "refractory" cases of myeloma, i.e. not responsive to other treatments, I gather; and he said Gp H is doing stem cell work "all the time."

Bld pressure: 120/70; wt 165

June 1 '01 exam w/ Dr. Ginsberg--

Status quo on my blood tests, which is good news: the "slight anemia" platelet count 36, "statistically unchanged" from previous 37, and the hem⁺acrit unchanged, indicating the protein spike hasn't continued to go up. Further good protein news in the all-day urine test: my "tiny bit" was 150 milligrams, and the level of concern is a gram.

All in all, Dr. G talked me out of the bone marrow test I'd intended, given every other indicator toward MGUS rather than myeloma, particularly after the OK bone scan.

He wants to see me every four months across this first year--i.e., twice more--then every six months. Says he doesn't foresee this protein spike condition going away; 20% of people over 80 have an elevated level, 50% of people over 90.

Says myeloma is not hereditary. Says no physical symptoms come with MGUS; myeloma can produce aches, fatigue..

Bld pressure 122/60; wt 166.

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